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EL PAPEL DE LAS VARIABLES MODULADORAS EN EL MALESTAR DEL CUIDADOR

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THE ROLE OF MODULATING VARIABLES IN CAREGIVERS' DISTRESS

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1. Abstract

Drawing on the stress and coping model (e.g., Haley et al., 1987), the aim of this doctoral thesis has been to analyze, cross-sectional and longitudinally, the role of different modulating variables on dementia caregivers' distress. With these objectives, four different studies have been conducted, and, although they are presented independently, the obtained results may be considered jointly in the discussion.

First, in order to provide a common framework for the four studies, a general introduction, based on caregiving literature review, is presented. Second, the general purpose of this research is described, followed by the specific objetives of each of the studies.Third, the main methodological characteristics of the studies are presented. Then, each of the independent studies is presented, with their own introduction, method, data analysis, results and discussion sections. Finally, a general discussion and the main conclusions of the obtained results are described.

Participants in this research consisted of family caregivers of persons with dementia, who were recruited through different Social Services and Day Care centers from Madrid. Face to face interviews were conducted, assessing the following variables: stressors (frequency of behavioral problems, functional capacity, burden), resources (self-efficacy domains, motives for caring, emotional regulation strategies, rumination and cognitive reappraisal, and frequency and satisfaction with behavioral activation) and health outcomes (depression, anxiety, anger, and perceived physical health).

The objective of the first study was to analyze the moderating role of caregivers' self-efficacy domains in different points of the caregivers' stress process. Specifically, we analyzed the moderating role of self-efficacy for managing behavioral problems on the relationship between stressors (frequency of behavioral problems) and caregivers' burden. In addition, we analyzed the moderating role of self-efficacy for controlling upsetting

thoughts on the relationships between burden and caregivers' distress (depression, anxiety). Results showed no significant moderating effect of self-efficacy for managing behavioral problems in the relationship between stressors and burden. However, results showed that self-efficacy for controlling upsetting thoughts moderated the impact that burden has on caregivers' distress.

The purpose of the second study was to analyze the effects of motives for caring on the caregiving stress process. We analyzed the dimensional structure of the Cultural Justifications for Caregiving Scale-Revised (CJCS-R), a scale which measures diverse motives for caring, and also explored the effects of these motivations on caregivers' stressors, resources and mental health variables. Results showed a bidimensional structure of the scale, and factors were labeled, "Intrinsic motives" and "Extrinsic motives" for caring. In addition, considering simultaneosly caregivers´ scores (high or low) in both dimensions, four groups of caregivers were identified, finding that those caregivers with low scores on intrinsic motives and high scores on extrinsic motives reported having worse caregivers' resources (more rumination and less cognitive reappraisal) and worse consequences of caregiving (depression, anxiety and anger).

The third study was aimed at analyzing the effects of considering simultaneosly the frequency and satisfaction with behavioral activation in caregiver's stressors, resources, outcomes and risk of institutionalization. Results showed that caregivers with high levels of both frequency and satisfaction with behavioral activation showed better resources (rumiation and cognitive reappraisal) and outcomes (depression, anxiety, and, perceived physcial health) and low levels of risk of institutionalization. However, those caregivers with low levels of both frequency and satisfaction with behavioral activation were at greater risk of reporting poorer resources and outcomes.

The purpose of the fourth study was to analyze, longitudinally, if changes in caregivers' modulating variables predicted changes in caregivers' distress. Results showed that increases in caregivers' self-efficacy for controlling upsetting thoughts, frequency of leisure activities and cognitive reappraisal predicted decreases in caregivers' depression over time, even after controlling for gender and stressors.

Finally, considering the results of the four studies toghether, we highlight the usefulness of considering the multidimensionality of modulating variables, as well as the joint consideration of these dimensions for identifying caregivers at greater risk of suffering negative outcomes. We found two caregivers' profile at risk: caregivers with high levels of extrinsic motives for caring and low levels of intrinsic motives for caring and those with low levels of both frequency and satisfaction with behavioral activation.

2. Introducción general

En este apartado se exponen distintos aspectos relevantes sobre la situación en la que se encuentra el estudio del cuidado familiar de personas con demencia. En primer lugar, se comenta el punto de partida desde el que se enmarca esta tesis doctoral: el caso de una situación de estrés crónico, el cuidado familiar de personas con demencia. En segundo lugar, se realiza una exposición sobre la relevancia del estudio del cuidado familiar, así como sus posibles consecuencias. A continuación, se explica el modelo teórico en el que se basa este trabajo, a saber, el modelo de estrés y afrontamiento adaptado al cuidado, así como la importancia del estudio de las variables moduladoras en el proceso de estrés. Finalmente, se presentan las limitaciones y los retos futuros de la investigación en este campo, como punto de partida de los distintos estudios empíricos que componen esta tesis doctoral.

2.1 Punto de partida

Esta tesis doctoral se enmarca en un área de investigación que ha tenido mucha influencia y repercusión en el ámbito de la psicología clínica y de la salud: el estudio del estrés. Desde los comienzos del estudio del estrés a finales de los años 50 hasta la actualidad se han desarrollado distintas líneas de investigación que han abordado el estrés de maneras diferentes. En la actualidad, probablemente el planteamiento más completo y que mayor aceptación ha recibido en esta área sea el propuesto por Lazarus y Folkman (1984), quienes consideraron el estrés como el resultado de una interacción entre las personas y el ambiente o contexto en el que se sitúan. Según estos autores, un suceso será estresante en la medida en la que una persona lo perciba y valore como tal, independientemente de las características objetivas que presente. La valoración de la persona se realizará en función de la percepción de las demandas del ambiente y de los

recursos personales de los que disponga. Existen numerosas clasificaciones de los distintos tipos de estrés, siendo una de ellas la que se basa en los tipos de fuentes de estrés. Según esta clasificación, podemos distinguir entre: a) sucesos vitales intensos y extraordinarios (p.ej., separación o divorcio, ser despedido), que exigen a la persona un esfuerzo de adaptación muy intenso, que conlleva importantes respuestas de estrés; b) sucesos diarios estresantes de menor intensidad, donde se incluyen situaciones múltiples de la vida diaria cotidiana que generan respuestas de estrés y producen efectos negativos, no por su intensidad sino por su elevada frecuencia de aparición; y, finalmente, c) situaciones de tensión crónica mantenida, que se consideran situaciones capaces de generar estrés, que se mantienen durante períodos de tiempo largos (p.ej., enfermedades prolongadas) y con una elevada intensidad. Estos estresores son especialmente peligrosos porque combinan la elevada intensidad, con la larga duración, de manera que, a largo plazo, pueden generar problemas de salud físicos y psicológicos (p.ej., trastornos cardiovasculares, gastrointestinales, depresión, ansiedad, etc.).

Debido a que las demencias son trastornos neurodegenerativos, de larga duración, y, con sintomatología cambiante, el cuidado de personas mayores con demencia, ha sido señalado como una situación típica de estrés crónico. Por tanto, esta tesis doctoral se enmarca dentro del estudio del estrés crónico.

2.2 Investigación sobre el cuidado familiar de personas con demencia

Es un hecho conocido que en la sociedad actual que cada vez es mayor la esperanza de vida de las personas y que cada vez hay más personas mayores en nuestro país. Se calcula que existen en España 7.782.904 de personas mayores de 65 años (un 16.7% de la población total), de las cuales un 57.6% son mujeres y un 28% tienen más de 80 años (IMSERSO, 2010). Asimismo, según el Consejo de la Unión Europea (2008,

diciembre), entre los años 1995 y 2050, la población europea mayor de 65 años se duplicará. Debido a este envejecimiento de la población y la disminución de la tasa de natalidad, existe cada vez un mayor riesgo de que aparezca y se desarrolle algún tipo de dependencia (p.ej., debido a padecer una demencia), incrementándose por tanto el número de personas que necesitan algún tipo de ayuda. La prevalencia de las personas que tienen demencia en el mundo es de 35.6 millones de personas (Alzheimer's Disease International, 2009), con una tasa de incidencia de 4.6 millones de nuevos casos cada año, lo que representa un caso nuevo por cada 7 segundos (Ferry y otros, 2005). Asimismo, se estima que la prevalencia mundial de la enfermedad de Alzheimer se cuadriplique entre el año 2006 - cuya prevalencia estimada fue de 26.6 millones de personas- y el 2050 (Brookmeyer, Johnson, Ziegler-Graham y Arrighi, 2007), estimándose que en España 400.000 personas padecen Alzheimer (Pedro-Cuesta y otros, 2009). Asimismo, existen datos que sugieren que el diagnóstico de demencia está subestimado en un 50% de las personas mayores de 65 años (Boustani y otros, 2003). En nuestro país, se estima que sólo tres de cada diez casos de demencia son detectados por los servicios sanitarios, con proporciones de casos de demencia no detectados que, según el nivel de gravedad, oscilan entre un 36% en el caso de demencias graves, y un 95% en el caso de demencias leves (Pastor y otros, 2003).

Igualmente, debido a la reciente incorporación de la mujer al mercado laboral y a que cada vez las unidades familiares son de menor tamaño en nuestra sociedad, no es sorprendente el hecho de que cada vez tenga más relevancia el interés por considerar el papel de los cuidadores familiares de personas dependientes. A pesar de que es evidente que son necesarias redes de atención que cubran las necesidades de las personas dependientes, la combinación de los factores anteriormente mencionados, junto con la escasez de recursos formales disponibles para hacer frente a las necesidades de las

personas mayores (ej. centros de día) (Ministerio de Trabajo y Asuntos sociales, 2005; p. 139), hacen que la figura del cuidador informal o familiar esté en peligro. Según un estudio realizado en España con una muestra representativa de cuidadores familiares (IMSERSO, 2005), existen 1.226.181 de personas mayores de 65 años que reciben ayuda informal – es decir, familiares, amigos o conocidos que prestan ayuda a personas mayores sin recibir a cambio una retribución económica-, lo que representa un 17% de la población mayor de 65 años. La mayoría del cuidado de las personas dependientes (aproximadamente un 85%), es proporcionado por la familia (Whitlatch y Noelker, 1996). En nuestro país, un 6% de la población mayor de 18 años es cuidadora de personas mayores dependientes, representando un total de 950.528 personas (IMSERSO, 2005).

El perfil característico del cuidador familiar en nuestro país es el de una mujer que cuida de su padre o madre, casada, con estudios primarios y cuya actividad principal son las tareas del hogar (IMSERSO, 2005). Así, de las personas que prestan ayuda familiar a las personas mayores, el 83.6% son mujeres, el 50.2% son hijas, el 76.2% están casadas y el 43% tiene estudios primarios, siendo la edad media del cuidador informal de 52.9 años (IMSERSO, 2005). Los cuidadores atienden a sus familiares mayores dependientes una media de aproximadamente 11 horas diarias (IMSERSO, 2005) y, en los casos del cuidado de personas con demencia, la media de horas dedicadas al cuidado es de más de 70 a la semana (Weiss, González, Kabeto, y Langa, 2005).

Uno de los valores más apreciados por las políticas sociales y asistenciales de la atención a las personas mayores, y, especialmente, por las personas mayores, es el de "envejecer en casa" (IMSERSO, 2002). Así, el 87.3% de las personas mayores y el 65% de la sociedad española informan de que prefieren vivir en sus casas, y un 63.5% de las personas mayores prefiere ser cuidada por su familia en lugar de por cuidadores profesionales (IMSERSO, 2010). Igualmente, el mantenimiento del cuidado en el hogar

supone un gran reto para las políticas sociales y sanitarias, ya que no sólo tiene ventajas para las personas mayores, sino que supone un ahorro económico substancial para el estado, al estimarse que el valor medio del coste europeo de la enfermedad de Alzheimer es de 28.000 euros al año (Jönsson y Wimo, 2009). En nuestro país, el coste que invierten cuidadores familiares en el cuidado de sus allegados oscila entre los 2223 euros mensuales para los cuidadores de enfermos en fases iniciales, y los 3.114 euros para aquellos cuidadores de enfermos en fases de la enfermedad más avanzadas (Rivera, Casal y Currais, 2008).

Sin duda alguna, la aprobada Ley de Promoción de la Autonomía Personal y Atención a Personas en Situación de Dependencia (Ley 39/2006 de 14 de diciembre; Boletín Oficial del Estado, 2006) pone de manifiesto el destacado papel que los cuidadores familiares ejercen en nuestra sociedad y supone un paso importante hacia el camino de la optimización de la atención a las familias en situaciones de dependencia. El objetivo fundamental de esta ley fue el de "regular las condiciones básicas de promoción de la autonomía personal y de atención a las personas en situación de dependencia", a través de la creación de un Sistema para la Autonomía y Atención a la Dependencia (SAAD; p.ej., servicios de teleasistencia, centros de día, servicio de atención residencial), de manera que, según la valoración del grado de dependencia de la persona implicada, se determinan el tipo de prestaciones concretas para cada persona a través del diseño de un Plan Individual de Atención (PIA). Si bien es cierto que, esta ley resalta la necesidad de reformar y optimizar el sistema actual de atención sociosanitaria, con el avance que esto conlleva en la atención a las familias y las personas que están en situación de dependencia, igualmente, se han puesto de manifiesto distintas limitaciones, tales como; el carácter ambiguo e impreciso de sus implicaciones concretas, tanto para las familias como los profesionales y entidades específicos que lo implementarán; y la falta de claridad del

marco conceptual y de los criterios de calidad en los que se enmarcan las acciones derivadas de la ley (SEGG, 2006), así como de los ámbitos o entidades que integran los órganos de decisión en el diseño e implementación de modelos de formación (Losada, Márquez-González, Peñacoba, Gallagher-Thompson y Knight, 2007). Asimismo, existen estudios que sugieren que esta ley no tiene en cuenta la evidencia científica que, desde distintas disciplinas, se ha puesto de manifiesto en relación a la atención a las familias que cuidan de personas dependientes (Losada y otros, 2007; Garcés, Carretero, Ródenas y Alemán, 2010). De igual manera, en nuestro país, parece que son todavía escasos o insuficientes los recursos formales de los que disponen las familias que cuidan de sus seres queridos. Así, según datos del IMSERSO (2010), sólo un 5.8% de las personas mayores cuenta con servicios de ayuda a domicilio, un 6% con centros de día y un 6.8% con teleasistencia. En este sentido, Garcés y otros, (2010) recomiendan que, para maximizar la eficiencia de los servicios sociales en cuanto a su papel en la disminución de la carga del cuidador, es necesario, por un lado, ampliar tanto el tipo de servicios proporcionados por el sistema social como la duración de su ayuda prestada en el hogar; y, por el otro, potenciar las intervenciones psicológicas, especialmente programas psicoeducativos para el entrenamiento en manejo de estrategias y habilidades para afrontar el cuidado, para cubrir las necesidades de los cuidadores principales y disminuir así sus niveles de malestar (Garcés y otros, 2010).

2.3 Consecuencias del cuidado familiar

Distintos metanálisis y revisiones de los estudios realizados con cuidadores familiares de personas mayores con demencia han proporcionado evidencia sólida que permite afirmar que éstos presentan mayores niveles de malestar (depresión, ansiedad, estrés, menor bienestar subjetivo) que los cuidadores de personas con problemas

funcionales y que los no cuidadores (p.ej., Pinquart y Sörensen, 2003; Schulz, O´Brien, Bookwala, y Fleissner, 1995). Uno de cada tres cuidadores de personas con demencia tiene depresión y los cuidadores de personas con demencia tienen más probabilidad de desarrollar depresión que los cuidadores de personas con otras enfermedades crónicas (Schoenmakers, Buntinx y Delepeleire, 2010). Igualmente, existen datos que avalan que las diferencias encontradas en los niveles de sintomatología depresiva entre los cuidadores y no cuidadores, con mayores niveles encontrados de depresión por parte los cuidadores, se mantienen a lo largo del tiempo (p.ej., Roth, Haley, Owen, Clay y Goode, 2001). Los estudios que analizan la salud mental de los cuidadores longitudinalmente, si bien son escasos, sugieren que la sintomatología depresiva tiende a mantenerse a lo largo del tiempo (Clay, Roth, Wadley y Haley, 2008), o incluso incrementarse, como se encontró en un estudio en el que los hombres que informaban de una disminución del apoyo social recibido, presentaban niveles de depresión más elevados a lo largo del tiempo (Schulz y Williamson, 1991).

Igualmente, la literatura del cuidado relacionada con la salud física de los cuidadores incluye evidencia empírica amplia que sugiere los cuidadores de personas con demencia tienen consecuencias más negativas en su salud física que los no cuidadores (Vitaliano, Zhang y Scalan, 2003). De esta forma, se ha encontrado que los cuidadores de personas con demencia tienen significativamente menores niveles de salud percibida global, mayores niveles de hormonas del estrés y menores niveles de anticuerpos que los no cuidadores (Vitaliano, y otros, 2003). Asimismo, se ha encontrado que los cuidadores de personas con demencia en situación de estrés tienen un riesgo de mortalidad 63% mayor que los no cuidadores (Schulz y Beach, 1999). Por su parte, Mausbach y otros (2008), en un estudio longitudinal, encontraron que los aumentos en el estrés del cuidador se asociaban significativamente con una mayor desensibilización en los receptores

adrenérgicos β2, aumentando así el riesgo de desarrollar problemas cardiovasculares (p.ej., hipertension). Asimismo, distintos estudios revelan que el malestar de los cuidadores no sólo tiene influencias negativas en la salud física de los cuidadores (p.ej., Mausbach, Patterson, Rabinowitz, Grant & Schulz, 2007), sino que también parece tener repercusiones sobre la persona cuidada, al ser un predictor significativo del riesgo de institucionalización (Gaugler, Kane, Kane, y Newcomer, R., 2006; Gaugler, Yu, Krichbaum y Wyman, 2009).

Si bien es cierto que la investigación es consistente al mostrar que ser cuidador se asocia con consecuencias negativas para la salud psicológica y física de los cuidadores, parece que la variable ser cuidador por sí misma explica menos de un 8% de la varianza de su salud física y psicológica, habiéndose encontrado porcentajes de varianza de 7.8 y 0.8 para la depresión y la salud física de los cuidadores, respectivamente (Pinquart y Sörensen, 2003). En este sentido, parece que son otras variables relacionadas con las características del cuidador y de la persona cuidada las que parecen tener un papel más relevante en la explicación de por qué si los cuidadores se enfrentan a situaciones similares, no todos presentan el mismo grado (frecuencia e intensidad) de malestar, variables que encajan en modelos teóricos como el que se detalla a continuación.

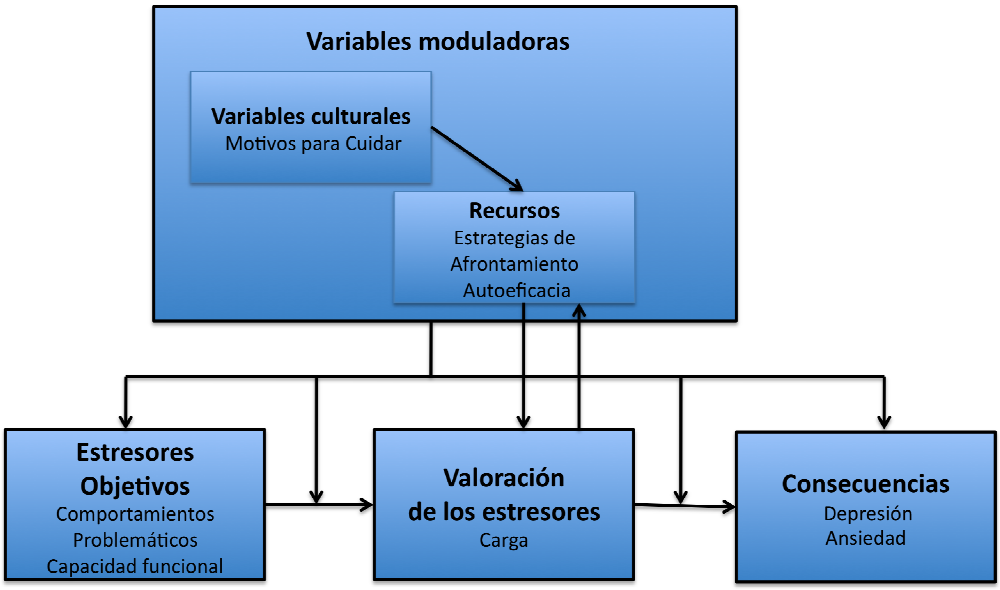
2.4 El modelo de estrés y afrontamiento: un marco teórico para explicar el malestar del cuidado

Tal y como se ha comentado previamente, debido a las considerables demandas asociadas a ser cuidador, que se desempeñan durante un periodo de tiempo prolongado (durante una media de 10 años, aproximadamente), con un elevado número de horas diarias dedicadas al cuidado (más de 70 horas semanales; Weiss y otros, 2005), el proceso del cuidado ha sido considerado como un ejemplo prototípico de situación de estrés

crónico (Vitaliano, Young y Zhang, 2004). Por tanto, no es sorprendente que en el estudio del proceso del cuidado y sus consecuencias, el modelo teórico más comúnmente utilizado haya sido el modelo teórico de estrés y afrontamiento (Lazarus y Folkman, 1984) adaptado al cuidado (Haley, Levine, Brown, y Bartolucci, 1987; Pearlin, Mullan, Semple y Skaff, 1990). Sin lugar a dudas, el modelo de estrés y afrontamiento adaptado al cuidado (Haley y otros, 1987; Pearlin y otros, 1990) es el marco teórico desde el cual se han llevado a cabo la mayoría de los estudios que han analizado los mecanismos implicados en las consecuencias psicológicas del cuidado y ha recibido importante apoyo empírico tanto en estudios transversales (Hilgeman y otros, 2009) como de intervención (Burgio y otros, 2003). Si bien es cierto que la investigación es consistente acerca de las consecuencias negativas que el cuidado de personas con demencia genera sobre los cuidadores familiares, son escasos los estudios que analizan cuáles son los mecanismos específicos que influyen en el desarrollo y mantenimiento de estas consecuencias (Pinquart y Sörensen, 2006; Schulz y otros, 2005).

De acuerdo con este modelo, los estresores objetivos a los que se ven sometidos los cuidadores (por ejemplo, la frecuencia de comportamientos problemáticos o la capacidad funcional del familiar) no determinan directamente las consecuencias negativas del cuidador, sino que esta relación se ve influida por la valoración que hace el cuidador de los estresores, en función de los recursos de los que disponga. En la Figura 2.1, se muestra un esquema del modelo teórico de estrés aplicado al cuidado basado en los modelos Pearlin y otros (1990), Haley y otros (1987) y Knight y Sayegh (2010).

Figura 2. 1. Modelo de estrés aplicado al cuidado.



Nota. El modelo que aquí se presenta incluye sólo aquellas variables que se consideran clave en los modelos téoricos en los que se basa. Existen otras variables que han de tenerse en cuenta en los estudios, (p.ej. variables sociodemográficas y contextuales) que por simplificación, no se han incluido en el modelo.

Los estresores objetivos hacen referencia a las demandas y dificultades a las que se enfrentan los cuidadores en la situación de cuidado, tales como el nivel de dependencia de la persona cuidada o grado en que necesita ayuda para realizar las actividades básicas o instrumentales de la vida diaria o la frecuencia de sus comportamientos problemáticos (ej. agresividad, problemas de memoria, etc.).

Por su parte, las variables moduladoras (que pueden ser variables mediadoras o moderadoras) son los factores (externos- p.ej., variables culturales o internos-p.ej., psicológicos) que influyen sobre el tipo e intensidad de las consecuencias del cuidado en la vida del cuidador, y pueden actuar atenuando o disminuyendo las consecuencias negativas o potenciando las positivas. Así, estas variables son las que en gran medida contribuyen a explicar por qué ante una situación similar (ser el cuidador principal de una persona con demencia) existen diferencias entre cuidadores en las consecuencias psicológicas y físicas asociadas al cuidado. Por este motivo, las variables moduladoras son

consideradas habitualmente como los mecanismos de acción que intervienen en el proceso de estrés, siendo, por tanto, las variables clave susceptibles de ser modificadas y potenciales focos de intervención para reducir el malestar de los cuidadores (Gitlin y otros, 2000).

Dichos recursos o variables moduladoras influyen en la valoración o evaluación subjetiva que hace el cuidador de los estresores objetivos, que habitualmente es denominada como estrés subjetivo (p.ej., carga) (Lawton, Moss, Kleban, Glicksman y Rovine, 1991). En este sentido, también existen estudios que consideran la carga como una variable moduladora (Montorio, Izal, López-López y Colodrón, 1998), entendiéndola como la valoración o interpretación cognitiva del cuidador ante los estresores derivados del cuidado. Según los resultados de esta valoración, y, en función de los recursos y habilidades con los que cuente el cuidador, los cuidadores tendrán peores o mejores consecuencias. Finalmente, las consecuencias son los resultados que tiene el proceso de estrés en el funcionamiento psicológico, físico y social del cuidador, siendo la variable más estudiada la depresión.

Recientemente, algunos autores han sugerido la inclusión de variables culturales (p.ej., Pinquart y Sörensen, 2005) en el modelo de estrés y afrontamiento, proponiendo el modelo Sociocultural de Estrés y Afrontamiento (Knight y Sayegh, 2010). Knight y Sayegh (2010) sugieren un modelo teórico común a las distintas culturas, según el cual la relación entre los comportamientos problemáticos de los cuidadores, considerados como estresores, y sus niveles de malestar, estarían mediados por la carga subjetiva del cuidador. De este modo, mayores niveles de carga estarían asociados con peores consecuencias para la salud física y psicológica de los cuidadores. Igualmente, estos autores (Knight y Sayegh, 2010) sugieren que el efecto de los aspectos culturales en dicho modelo son complejos, multidireccionales e influyen a través de las estrategias de

afrontamiento y el apoyo social y no a través de la valoración subjetiva de los cuidadores, tal y como se había propuesto tradicionalmente.

Finalmente, existen otras variables (p.ej., variables contextuales) que influyen en el proceso del cuidado, y que, sin embargo, no se han incluido en el modelo representado, para una mayor simplificación del mismo. En este sentido, las variables contextuales, que hacen referencia a características sociodemográficas del cuidador y del familiar (ej. edad sexo, parentesco), su relación previa, etc., han de ser controladas en el estudio con cuidadores. Por último, es importante destacar que este modelo ha de considerarse no como un reflejo perfecto de la realidad, sino como una guía para la investigación en el cuidado (Pearlin y otros, 1990).

2.5 El estudio de las variables moduladoras en el proceso del cuidado

El estudio del papel de las variables moduladoras en el proceso de estrés tiene una especial relevancia en la investigación en el cuidado, dado que permite identificar aquellas variables sobre las que una potencial intervención conseguiría, presumiblemente, una reducción significativa del malestar de los cuidadores.

A continuación, se presenta una breve revisión de la literatura de los principales resultados encontrados sobre la influencia de diferentes variables moduladoras sobre el malestar del cuidador. Concretamente, se presentan las variables moduladoras más frecuentemente estudiadas, el apoyo social y las estrategias de afrontamiento consideradas como un constructo general. Igualmente, se presentan los resultados encontrados con variables que han recibido menos atención, o, que su papel en la literatura no está tan claro, como son la autoeficacia percibida del cuidador, la activación conductual, variables de regulación emocional, así como las variables culturales de familismo y motivos culturales para cuidar.

2.5.1 Apoyo social

Con respecto al apoyo social, distintos estudios han mostrado que esta variable tiene consecuencias positivas en el proceso de estrés del cuidado, ya que se han encontrado asociaciones con menores niveles de depresión (p.ej., Haley et al., 1996), de carga (p.ej., Harwood et al., 2000) y mayores niveles de satisfacción con la vida (p.ej., Kaufman, Kosberg, Leeper y Tang, 2010). Parece que es la calidad de dicho apoyo social y no la cantidad el factor más relevante a la hora de explicar el efecto del apoyo social sobre el malestar del cuidador, habiéndose encontrado datos que avalan relaciones negativas entre la satisfacción con el apoyo social y la depresión de los cuidadores (Clay, Roth, Wadley y Haley, 2008; López, 2004).

2.5.2 Estrategias de afrontamiento

Las estrategias de afrontamiento se han definido como los esfuerzos cognitivos y conductuales que emplean los cuidadores para solucionar o mejorar sus problemas y evitar o minimizar que se produzcan situaciones negativas en el día a día o consecuencias para su salud mental y física (ver, p.ej., Gottlieb y Wolfe, 2002). En relación con esta variable, distintos estudios aportan datos que sugieren que, mientras que el afrontamiento activo o centrado en el problema se asocia con menores niveles depresión del cuidador (p.ej., Haley y otros, 1987; Knight y Losada, in press), el afrontamiento de tipo evitativo se relaciona de forma positiva con la depresión (p.ej., Haley et al., 1996). Se ha sugerido que es más útil analizar específicamente cada una de las estrategias de afrontamiento por separado, en lugar de agruparlas en categorías tan amplias (Kneebone y Martin, 2003). La literatura refleja que, dentro de una misma categoría de estrategias de afrontamiento, se han incluido distintos tipos de estrategias que pueden tener consecuencias muy diferentes

entre sí para los cuidadores. En este sentido, Li, Seltzer y Greenberg (1999) analizaron la relación entre el uso de estrategias de afrontamiento centradas en el problema –compuesta por la suma de las estrategias de afrontamiento activo, planificación, reevaluación cognitiva, disminuación de actividades de actividades- y la depresión del cuidador, y encontraron asociaciones significativas entre estas variables. Por otro lado, Cooper y otros (2008) encontraron que utilizar estrategias más centradas en la emoción –aceptación, humor, reevaluación cognitiva y religión- predecían mayores niveles de ansiedad en los cuidadores. Es relevante señalar que, mientras que en el estudio de Li y otros (1999), se considera la reevaluación cognitiva como una estrategia típica de afrontamiento centrado en el problema, en el estudio de Cooper y otros (2008) es considerada como una estrategia de afrontamiento centrada en la emoción.

Como el constructo de estrategias de afrontamiento considerado de forma general resulta menos predictivo que el análisis más específico de variables, a continuación se describen independientemente distintos estudios que han analizado las variables de activación conductual y las estrategias de regulación emocional en relación con el malestar del cuidador:

a) Activación conductual

Con respecto al análisis del impacto de la activación conductual en el malestar del cuidador, la mayoría de los estudios se han centrado en analizar o bien la frecuencia de las actividades agradables o bien la satisfacción con el ocio, habiéndose encontrado efectos positivos de ambas variables sobre el malestar del cuidador (López, López-Arrieta & Crespo, 2005; Losada et al., 2010). Sin embargo, recientemente algunos investigadores han resaltado la importancia de considerar ambas dimensiones del ocio de forma simultánea, esto es, la frecuencia y satisfacción (p.ej., Benyamini, y Lomranz, 2004;

Mausbach y otros, 2008) para predecir de forma más precisa el malestar psicológico de los cuidadores. En este sentido, Mausbach, Roepke, Depp, Patterson and Grant (en prensa) han desarrollado el modelo teórico "PEAR" ("Pleasant Events and Activity Restriction model"), desde el cual se sugiere que niveles bajos de frecuencia de actividades agradables y niveles altos de percepción de restricción con actividades agradables, predicen mayores niveles de malestar y mayor uso de estrategias de afrontamiento desadaptativas en los cuidadores (Mausbach et al., in press). Hasta la fecha, no existen estudios que analicen el efecto del perfil de ocio del cuidador -considerando tanto la frecuencia como la satisfacción simultáneamente- en el malestar del cuidador.

b) Estrategias de regulación emocional

Sin embargo, menos atención han recibido, las estrategias de regulación emocional (p.ej., rumiación) en el estudio del proceso de estrés del cuidado de personas con demencia. En este sentido, a pesar de que existen estudios realizados con población no cuidadora que encuentran que el empleo más frecuente de estrategias de regulación emocional desadaptativas (mayores niveles de rumiación o menor uso de la reevaluación cognitiva), se asocia con mayores niveles de depresión y ansiedad (Carver, Scheir, y Weintraub, 1989; David y Nolen-Hoeksema, 2000), no existen apenas estudios que analicen su relación con el malestar en la población de cuidadores de personas con demencia.

2.5.3 Autoeficacia percibida

En cuanto a la autoeficacia percibida del cuidador, se ha encontrado que puntuaciones altas en esta variable se asocian con menores niveles de depresión (Fortinsky, Kercher y Burant, 2002) y ansiedad (Laserna et al., 1997) en los cuidadores.

Sin embargo, con respecto a su papel moderador en la relación entre los estresores y el malestar del cuidador, los estudios existentes son incongruentes. Por un lado, mientras que Gilliam y Steffen (2006) no encontraron un efecto moderador de la autoeficacia en la relación entre comportamientos problemáticos y depresión, recientemente, Rabinowitz, Mausbach y Gallagher-Thompson (2009) encontraron que la autoeficacia para manejar comportamientos problemáticos moderaba la relación entre comportamientos problemáticos y la depresión en cuidadores de personas con demencia. Son necesarios más estudios que analicen cuál es el efecto moderador de la autoeficacia en la relación entre estresores y malestar del cuidador, especialmente teniendo en cuenta el modelo de estrés y afrontamiento.

2.5.4 Variables culturales

a) Familismo

Probablemente, la variable cultural moduladora más frecuentemente estudiada en el estudio del cuidado y sus consecuencias es el familismo -que hace referencia a sentimientos fuertes de lealtad, reciprocidad y solidaridad entre miembros de una misma familia. La evidencia empírica del estudio de la relación entre el familismo y el malestar de los cuidadores, muestra que, si bien se han encontrado asociaciones negativas entre esta variable y la carga y depresión en los cuidadores (Robinson y Knigth, 2004), también existen estudios que muestran su relación positiva con el malestar del cuidador (depresión) (Losada y otros, 2006). Recientemente, el carácter multidimensional del familismo ha recibido respaldo empírico (p.ej., Losada y otros, 2008), encontrándose que, mientras que el familismo relativo a la percepción de obligación familiar se asociaba positiva y significativamente con la depresión en los cuidadores, el familismo relativo a la percepción de apoyo familiar se asociaba de manera inversa con la depresión (Losada,

Márquez-González, Knight, Yanguas, Sayegh y Romero-Moreno, 2010). En este sentido, Knight y Sayegh (2010) sugieren que el análisis de las distintas dimensiones del familismo (familismo relativo valores de obligación vs valores de apoyo y solidaridad familiar) para explicar el malestar es más útil que analizarlo de forma unidimensional. En esta línea, recientemente, Sayegh y Knight (2010) han encontrado que, mientras que la dimensión de familismo relativa a la percepción de obligación tenía efectos negativos sobre la salud mental y física de los cuidadores, la dimensión relacionada con apoyo familiar no tenía ningún efecto sobre estas variables (Sayegh y Knight, 2010).

b) Motivos culturales para cuidar

Igualmente, si bien en los últimos años se ha producido un incremento significativo en el número de trabajos realizados sobre la influencia de aspectos culturales en el cuidado (para una revisión, ver Janevic y Connell, 2001 o Pinquart y Sörensen, 2005), son todavía escasos los estudios que analizan la forma en la que variables culturales específicas, como son los motivos o razones culturales para cuidar, influyen en el proceso de estrés del cuidado.

En una reciente revisión (Quinn, Clare y Woods, 2010), se pone de manifiesto la limitada existencia de estudios que analicen los efectos de los motivos para cuidar en el malestar del cuidador, destacando sobretodo, sus limitaciones metodológicas, como la falta de instrumentos de medida validados para esta variable, así como de un modelo teórico de partida para su estudio (Quinn y otros, 2010). En este sentido, la única escala con adecuadas propiedades psicométicas diseñada específicamente para evaluar motivos para cuidar en cuidadores de personas con demencia, es la Escala de Justificaciones Culturales para el Cuidado (Cultural Justifications for Caregiving Scale, CJCS; Dilworth-Anderson y otros, 2004). Si bien en un estudio inicial realizado con la mencionada escala,

Dilworth-Anderson y otros (1999) encontraron que los motivos culturales relacionados con un mayor sentido de obligación no se asociaban con el malestar emocional del cuidador, esta misma autora, posteriormente, encontró que esta variable predecía peores niveles de salud psicosocial al cabo de un año y medio en cuidadores (Dilworth-Anderson y otros, 2004, 2005), no estando claro cuál es el papel que tienen sobre el malestar del cuidador. Igualmente, se ha encontrado apoyo empírico de la asociación entre distintos tipos de motivos y el malestar del cuidador. Así, existe evidencia que muestra que los motivos más relacionados con aspectos extrínsecos (p.ej., obligación, expectativa social) se asocian de forma positiva con el malestar del cuidador, mientras que motivos más relacionados con valores intrínsecos o personales (ej. por vinculación emocional, apoyo familiar) se asocian de forma negativa (Cicirelli y otros, 1993; Knight y Sayegh, 2010; Lyonette y Yardley, 2003).

Asimismo, siguiendo el modelo de estrés y afrontamiento, apenas existen estudios en los que se haya analizado el papel de variables moduladoras en el malestar del cuidador de forma longitudinal. El objetivo principal de los escasos estudios longitudinales que existen ha sido el de llevar a cabo un seguimiento del malestar del cuidador durante un período de tiempo específico (Gaugler y otros, 2005; Shaw y otros; 2003; Vitaliano y otros, 2005) y no se analiza concretamente qué variables contribuyen a explicar en mayor medida el aumento del malestar de los cuidadores a lo largo del tiempo.

2.6 Limitaciones y retos en la investigación sobre el cuidado

En base a la revisión realizada de la literatura, se observan, por un lado, aspectos que han sido bastante clarificados por la investigación, y, por otro lado, algunas lagunas o cuestiones pendientes que necesitan ser aclaradas en este ámbito de investigación.

En primer lugar, la investigación es consistente en afirmar que la situación de cuidar de personas con demencia tiene consecuencias negativas para la salud mental y física de los cuidadores (Pinquart y Sörensen, 2003; Schulz y otros, 1995). Igualmente, la mayoría de la investigación sobre el cuidado se ha basado en el modelo de estrés y afrontamiento adaptado al cuidado (Haley y otros, 1987; Pearlin y otros, 1990), el cual ha recibido suficiente apoyo empírico. En cuanto al estudio en el proceso de estrés de las variables moduladoras, las cuales influyen en la relación entre los estresores y las consecuencias del cuidado, las más frecuentemente analizadas han sido el apoyo social y las estrategias de afrontamiento de los cuidadores. Sin embargo, en la investigación sobre el cuidado, menos atención se ha prestado a otras variables (p.ej., activación conductual, regulación emocional del cuidador) o a su papel específico en el proceso de estrés (p.ej., papel moderador de la autoeficacia).

Igualmente, si bien recientemente se ha resaltado la importancia de considerar variables culturales en el modelo de estrés y afrontamiento (Pinquart y Sörensen, 2005), habiéndose desarrollado adaptaciones como el modelo sociocultural de estrés y afrontamiento (Knight y Sayegh, 2010), son escasos los estudios que analizan el papel de variables culturales específicas en él. En este sentido, la variable cultural más frecuentemente analizada en el estudio del cuidado ha sido el *familismo*, y los estudios apoyan la consideración multidimensionalidad de esta variable para explicar los distintos efectos encontrados en el malestar del cuidador (Sayegh y Knight, 2010). Sin embargo, es evidente que la variable cultural *motivos para cuidar*, ha recibido escasa atención en la literatura. En este sentido, se ha destacado la falta de instrumentos de medida fiables y válidos existentes para esta variable (Quinn y otros, 2010), así como, la contradicción en los resultados encontrados en cuanto a su papel en el malestar del cuidador, habiéndose

mostrado efectos tanto positivos como negativos (Dilworth-Anderson y otros, 1999; Dilworth-Anderson y otros, 2005).

Asimismo, los escasos estudios longitudinales realizados en el cuidado se han centrado en analizar la estabilidad del malestar del cuidador a lo largo del tiempo y examinar la influencia de los estresores del cuidador en su nivel de malestar. Sin embargo, son escasos los estudios que analizan el posible papel que distintas variables moduladoras tienen sobre el malestar del cuidador, basándose en el modelo de estrés y afrontamiento.

Finalmente, atendiendo a la revisión de la literatura realizada, se observa que, si bien se ha destacado la importancia de considerar la multidimensionalidad de algunas variables moduladoras, no existen estudios que analicen el efecto de estas dimensiones en distintos momentos del proceso de estrés, ni que consideren la combinación entre sí de las subdimensiones que componen un mismo constructo, para explicar el malestar del cuidador.

Mediante esta tesis doctoral se pretende dar un paso más en el conocimiento sobre estas cuestiones pendientes de aclarar en la investigación sobre el cuidado. Para ello, se han realizado cuatro estudios empíricos, cuyos objetivos se detallan a continuación.

3. Objetivos e hipótesis

3.1 Objetivo general de la Tesis Doctoral

La presente tesis tiene por objetivo general analizar, desde el marco teórico ofrecido por el modelo de estrés y afrontamiento adaptado al cuidado (p.ej., Haley et al., 1987), el papel que tienen distintas variables moduladoras en el proceso de estrés del cuidado y en la explicación del malestar de los cuidadores familiares de personas con demencia. Asimismo, se pretende analizar con metodología longitudinal cuáles son las variables moduladoras que predicen el malestar del cuidador. Concretamente, se analizará el papel de los motivos para el cuidado, la autoeficacia percibida, la activación conductual y la satisfacción con la misma y dos estrategias de regulación emocional, rumiación emocional y reevaluación cognitiva, en el malestar del cuidador. Para ello, se realizarán cuatro estudios independientes, cuyos objetivos específicos se detallan a continuación.

3.2 Estudio 1: El efecto moderador de las dimensiones de la autoeficacia en diferentes puntos del proceso de estrés del cuidado de personas con demencia

3.2.1 Objetivo general

Analizar el papel moderador de dos dimensiones de la autoeficacia percibida, a saber, la autoeficacia para manejar comportamientos problemáticos y para controlar pensamientos negativos, en el proceso de estrés del cuidador.

3.2.2 Objetivos específicos

1. Analizar el papel moderador de la autoeficacia para manejar comportamientos problemáticos en la relación entre estresores objetivos (frecuencia de comportamientos problemáticos) y subjetivos (carga).

2. Analizar el papel moderador de la autoeficacia para controlar pensamientos negativos en la relación entre la carga y el malestar del cuidador (depresión y ansiedad).
3. Analizar las relaciones existentes entre las dos dimensiones de la autoeficacia y las diferentes dimensiones del proceso de estrés, esto es, estresores (frecuencia de comportamientos problemáticos, capacidad funcional y carga) y malestar del cuidador (depresión y ansiedad).

3.2.3 Hipótesis

1. La autoeficacia para manejar comportamientos problemáticos tendrá un papel moderador en la relación entre frecuencia de comportamientos problemáticos y carga.
2. La autoeficacia para controlar pensamientos negativos tendrá un papel moderador en la relación entre carga y malestar (depresión y ansiedad) del cuidador.
3. Las distintas dimensiones de la autoeficacia se asociarán de forma inversa y significativa tanto con los estresores del cuidador, así como con su malestar.

3.3 Estudio 2: Motivos para cuidar: Relación con dimensiones de estrés y afrontamiento

3.3.1 Objetivo general

Analizar las propiedades psicométricas de la Escala *Justificaciones Culturales para el Cuidado-Revisada* (CJCS-R; Dilworth-Anderson, 2004) y la relación de los motivos para cuidar con variables centrales en el proceso de estrés del cuidado, especialmente, el malestar del cuidador.

3.3.2 Objetivos específicos

1. Realizar un análisis factorial exploratorio de la Escala de Justificaciones Culturales para el Cuidado-Revisada (CJCS-R; Dilworth-Anderson, 2004).
2. Analizar la relación existente entre motivos culturales y las variables de regulación emocional rumiación y reevaluación cognitiva (variables moduladoras).
3. Analizar la relación existente entre motivos culturales y el malestar psicológico del cuidador (depresión, ansiedad e ira).

3.3.3 Hipótesis

1. En consonancia con lo encontrado en estudios previos (ej., Dilworth-Anderson, 2005), se espera que la estructura factorial de la escala Justificaciones Culturales para el Cuidado-Revisada sea unidimensional.
2. Dado que, de acuerdo con otros estudios (Dilworth-Anderson, 2004), una mayor puntuación en motivos para el cuidado se asocia a mayor sentido de obligación, se espera encontrar que dicha puntuación se asocie significativamente con un mayor uso de la estrategias de regulación emocional rumiación y un menor uso de la reevaluación cognitiva.
3. Se encontrará una asociación significativa y positiva entre la puntuación obtenida en la variable motivos para el cuidado y el malestar del cuidador.

3.4 Estudio 3: Efectos del perfil de frecuencia y satisfacción con el ocio en el malestar de cuidadores de personas con demencia

3.4.1 Objetivo general

Analizar de forma conjunta el papel de la frecuencia y la satisfacción con la activación conductual en la explicación del malestar del cuidador, siguiendo el modelo teórico "PEAR" (Pleasent Events, Activity Restriction) propuesto por Mausbach, Roepke, Depp, Patterson y Grant (en prensa) y el modelo de estrés y afrontamiento (Haley y otros, 1987).

3.4.2 Objetivos específicos

Se partirá de la clasificación de los participantes en función de sus niveles en las variables activación conductuctual y satisfacción con la activación conductual, analizando las diferencias entre los cuatro posibles perfiles que resultan de la combinación de estas dos variables: 1. cuidadores con bajos niveles de activación conductual y bajos niveles de satisfacción con la activación conductual; 2. cuidadores con bajos niveles de activación conductual y altos niveles de satisfacción con la activación conductual; 3. cuidadores con altos niveles de activación conductual y bajos de satisfacción con la activación conductual; 4. cuidadores con niveles altos en ambas variables. Concretamente, los objetivos son:

1. Analizar las diferencias entre los cuatro grupos en el malestar informado por los cuidadores (depresión, ansiedad y salud física percibida).
2. Analizar las diferencias entre los cuatro grupos en las variables moduladoras rumiación y reevaluación cognitiva.
3. Analizar dichas diferencias en los estresores del cuidador (horas diarias de cuidado, tiempo cuidando, capacidad funcional de la persona cuidada y frecuencia de comportamientos problemáticos).
4. Analizar las diferencias entre los cuatro grupos en el deseo de institucionalización de la persona cuidada.

3.4.3 Hipótesis

Los cuidadores con baja activación conductual y baja satisfacción con la actividad conductual, tendrán, en comparación con los otros tres grupos, significativamente:

1. Mayores puntuaciones en estresores (horas diarias de cuidado, tiempo cuidando, capacidad funcional de la persona cuidada y frecuencia de comportamientos problemático).
2. Mayores niveles de malestar (depresión, ansiedad y peor salud física percibida).
3. Mayor frecuencia de empleo de estrategias de regulación emocional disfuncionales (mayores niveles de rumiación emocional y menores niveles de reevaluación cognitiva).
4. Mayor deseo de institucionalización del familiar.

3.5 Estudio 4: Variables moduladoras y depresión: Un estudio longitudinal en cuidadores de personas con demencia

3.5.1 Objetivo general

Analizar el papel de distintas variables moduladoras en la explicación del malestar del cuidador a través de un diseño longitudinal.

3.5.2 Objetivos específicos

1. Analizar en qué medida las variaciones en autoeficacia para controlar pensamientos negativos a lo largo del tiempo (1 año), predicen variaciones en la depresión del cuidador, controlando el género del cuidador y los estresores objetivos (frecuencia de comportamientos problemáticos).

2. Analizar en qué medida las variaciones en la activación conductual a lo largo del tiempo predicen variaciones en la depresión del cuidador, controlando el género del cuidador y los estresores objetivos.
3. Analizar en qué medida las variaciones en la estrategia de regulación emocional reevaluación cognitiva a lo largo del tiempo, predicen variaciones en la depresión del cuidador, controlando el género del cuidador y los estresores objetivos.
4. Analizar si la inclusión de las variables moduladoras autoeficacia percibida, activación conductual y reevaluación cognitiva, incrementa de forma significativa el porcentaje de varianza explicada por las variables género y estresores (frecuencia de comportamientos problemáticos) de la depresión a lo largo del tiempo de los cuidadores.
5. Analizar si las variaciones en la frecuencia de comportamientos problemáticos (estresores) a lo largo del tiempo, predicen las variaciones en la depresión del cuidador.
6. Analizar si existen diferencias de género en la depresión a lo largo del tiempo.

3.5.3 Hipótesis

Teniendo en cuenta el modelo de estrés y afrontamiento (Haley et al., 1987) y en base a los resultados obtenidos en estudios transversales previos (Losada y otros, 2010; Márquez-González y otros, 2009; Romero-Moreno y otros, en prensa), se hipotetiza lo siguiente:

1. Los descensos en la autoeficacia para controlar pensamientos negativos a lo largo del tiempo se asociarán de forma significativa con aumentos en el nivel de depresión de los cuidadores.

2. Los descensos en la activación conductual a lo largo del tiempo predecirán de forma significativa aumentos en el nivel de depresión de los cuidadores.
3. Los descensos en el uso de la estrategia de regulación emocional reevaluación cognitiva a lo largo del tiempo se asociarán significativamente con aumentos en depresión de los cuidadores.
4. La inclusión de las variables moduladoras autoeficacia para controlar pensamientos negativos, activación conductual y reevaluación cognitiva incrementará de forma significativa el porcentaje de varianza explicada por otras variables, género y estresores (frecuencia de comportamientos problemáticos) en la depresión de los cuidadores a lo largo del tiempo.
5. Los aumentos en la frecuencia de comportamientos problemáticos a lo largo del tiempo se asociarán de forma significativa con aumentos en depresión de los cuidadores.
6. De acuerdo con estudios previos (p.ej.,Schulz y Williamson, 1991) las mujeres informarán de niveles superiores de depresión a lo largo del tiempo que los hombres.

4. Metodología general

Como se ha comentado previamente, esta Tesis Doctoral está formada por cuatro trabajos independientes que, aunque relacionados entre sí, comparten el objetivo general de analizar el papel que tienen distintas variables moduladoras en el proceso de estrés del cuidador. El estudio uno y dos han sido aceptados para su publicación, en las revistas *Aging and Mental Health* e *International Psychogeriatrics*, respectivamente, ambas indexadas en la base de datos ISI Web of Knowledge, en el segundo y primer cuartiles de la sección de Gerontología. Los estudios tres y cuatro están en fase de primer envío a revistas científicas, siendo las revistas objetivo *Behaviour Research & Therapy* y *Journals of Gerontology: Psychological Sciences*. De manera que, si bien cada uno de los artículos está integrado por sus propias secciones de Introducción, Método, Análisis de datos, Resultados, Discusión y Referencias, en este apartado, se van a describir las características de la metodología general compartidas por todos ellos. En primer lugar, se describen las características de las personas que han participado en estos estudios, así como el procedimiento utilizado para la recogida de la muestra. A continuación, se presentan los instrumentos de medida empleados. Finalmente, se describen los principales análisis de datos realizados para cada uno de los estudios.

Con el objetivo de ofrecer una visión general de las principales características de los cuatro estudios empíricos que componen esta Tesis Doctoral, se muestra un cuadro resumen de las mismas en la Tabla 4.1.

Tabla 4. 1. Resumen general de las características principales de los cuatro estudios empíricos.

Título	Autores	Estado del artículo	Muestra	Variables evaluadas	Análisis de datos
Estudio 1 Analysis of the moderating effect of self-efficacy domains in different points of the dementia caregiving process	Romero-Moreno, R., Losada, A., Mausbach, B.T., Márquez-González, Patterson, T.L., y López, J.	Aceptado en la revista *Aging and Mental Health*	N = 167	Frecuencia de comportamientos problemáticos Capacidad funcional Carga Autoeficacia para manejar comportamientos problemáticos Autoeficacia para controla pensamientos negativos Depresión Ansiedad	Análisis de moderación Pruebas de significación pos-hoc Correlaciones de Pearson
Estudio 2 Motives for caring: relationship to stress and coping dimensions	Romero-Moreno, R., Márquez-González, Losada, A., y López, J.	Aceptado en la revista *International Psychogeriatrics*	N = 166	Frecuencia de comportamientos problemáticos Motivos culturales para cuidar Rumiación Reevaluación cognitiva Depresión Ansiedad Ira	Análisis factorial exploratorio (rotación varimax) Análisis ANOVA y Chi Cuadrado Correlaciones de Pearson
Estudio 3 Effects of the frequency and satisfaction with leisure profile on dementia caregivers distress	Romero-Moreno, R., Losada, A., Márquez-González, M., y Mausbach, B.T.	En revisión. Revista objetivo: Behaviour Resarch & Therapy	N = 275	Frecuencia de comportamientos problemáticos Capacidad funcional Frecuencia y satisfacción con la activación conductual Rumiación Reevaluación cognitiva Depresión Ansiedad Salud física percibida Riesgo de institucionalización	Análisis MANOVA, ANOVA y Chi Cuadrado Correlaciones de Pearson
Estudio 4 Variables moodulating depression in dementia caregivers: a longitudinal study	Romero-Moreno, R., Márquez-González, Mausbach, B.T., y Losada, A.	En revisión: Revista objetivo: Journals of Gerontology: Psychological Sciences	Evaluación Pre o línea base (N = 190) Evaluación Post a los 3 meses (N =117) Evaluación de Seguimiento al cabo de un año (N =84)	Frecuencia de comportamientos problemáticos Autoeficacia para controlar pensamientos negativos Frecuencia de activación conductual Reevaluación cognitiva Depresión	Modelos generales lineales mixtos

4.1 Participantes y procedimiento

Los criterios de selección para participar en todos los estudios fueron los siguientes:

- Identificarse como el cuidador principal del familiar diagnosticado con Alzheimer u otra demencia relacionada.
- Ser familiar, amigo o vecino de la persona cuidada.
- Dedicar, al menos, 1 hora al día al cuidado del familiar enfermo.
- Llevar al menos 3 meses cuidando al familiar enfermo.

Se contactó con los cuidadores a través de distintos centros colaboradores situados en la Comunidad de Madrid (Servicios Sociales de Fuencarral-El Pardo, Servicios Sociales de Pozuelo de Alarcón, centro Reina Sofía de Cruz Roja, Asociación de Familiares de Alcobendas y de Arganda del Rey y Fundación María Wolff) y a través de anuncios en los medios de comunicación (p. ej., Internet o radio y televisión). Los diferentes centros proporcionaron los datos de contacto al equipo investigador. Se realizó una llamada telefónica para comprobar que el cuidador cumplía los criterios de inclusión y para concertar una cita en el centro para realizar la entrevista de evaluación de las variables de interés para el estudio. Psicólogos especializados en evaluación con cuidadores realizaron entrevistas individualizadas "cara a cara" de aproximadamente una hora y media de duración para medir las distintas variables del estudio. Todos los participantes proporcionaron el consentimiento informado, y el estudio fue aprobado por el Ministerio de Educación y el comité ético de la Universidad Rey Juan Carlos.

Debido a que esta tesis doctoral se ha desarrollado en el marco de diferentes proyectos de investigación, dirigidos, por un lado, a analizar los efectos del cuidado sobre las consecuencias psicosociales de los cuidadores y, por otro, a desarrollar una intervención psicoeducativa para cuidadores (ver, por ejemplo, Losada, Márquez-

González y Romero-Moreno, en prensa), el tamaño de la muestra de los distintos estudios es diferente. En este sentido, en los Estudios 1 y 2 participaron un total de 167 y 166, respectivamente. En el Estudio 3, participaron 275 cuidadores. El motivo principal de que en los Estudios 1 y 2 exista menor número de participantes tiene que ver con la decisión de evaluar algunas de las variables correspondientes a estos estudios en fases posteriores de los proyectos en los que se desarrolló esta investigación. Finalmente, aunque los detalles de los participantes del Estudio 4, de carácter longitudinal, se describen en la sección propia de método de este mismo estudio, los participantes en las distintas fases de este estudio fueron 190 cuidadores en la línea base (evaluación pre-intervención); 117 cuidadores tres meses después (evaluación post-intervención); y 84 cuidadores al cabo de un año posterior a la línea base (evaluaciones de seguimiento).

4.2 Variables e instrumentos de medida utilizados

A continuación se presentan los instrumentos de medida utilizados para los cuatro estudios (en el Anexo 1 se incluye una copia de cada uno de los instrumentos utilizados). La selección de variables a evaluar se ha realizado tomando como referencia el modelo de estrés adaptado al cuidado (Haley y otros, 1987; Knight y otros, 2000). Además de las variables sociodemográficas (p.ej., sexo, parentesco, edad del cuidador y de la persona cuidada, etc.), se evaluaron las variables que se describen a continuación:

4.2.1 Estresores objetivos

La ***frecuencia de comportamientos problemáticos*** de la persona cuidada se evaluó mediante el Listado de Problemas de Memoria y Conducta Revisado (RMPBC; Teri et al., 1992) y la ***capacidad funcional*** mediante el Índice de Barthel (Mahoney y Barthel, 1965).

4.2.2 Valoración de los estresores

La ***carga*** del cuidador se evaluó mediante la Entrevista de Carga de Zarit (Zarit, Reever and Bach-Peterson, 1980).

4.2.3 Variables moduladoras

Las subescalas de ***autoeficacia*** percibida para manejar comportamientos problemáticos y para controlar pensamientos negativos se evaluaron mediante la Escala Revisada de Autoeficacia del Cuidado adaptada al español (RSCSE; Steffen y otros, 2002). Los ***motivos culturales*** para cuidar fueron evaluados mediante la Escala de Justificaciones Culturales para el Cuidado-Revisada (CJCS-R, Dilworth-Anderson et al, 2004). En relación a las ***estrategias de regulación emocional***, para evaluar la *rumiación* se empleó el Cuestionario de Estilos de Respuesta a la Tristeza (RRS-versión reducida; Davis y Nolen-Hoeksema, 2000), mientras que la *reevaluación cognitiva* fue evaluada con ítems seleccionados de la escala Trait Meta-Mood (TMMS-24; Salovey y otros, 1995). Por su parte, la ***activación conductual y satisfacción*** con *la* ***activación conductual*** a través de la Escala de Frecuencia y Satisfacción con el Ocio y Tiempo Libre (LTS; Stevens y otros, 2004).

4.2.4 Variables de resultado: Consecuencias del cuidado

La ***sintomatología depresiva*** se evaluó mediante la Escala de Depresión del Centro para Estudios Epidemiológicos (CES-D; Radloff, 1977); la ***ansiedad*** a través de la subescala de Tensión del Perfil del Estado de Ánimo (POMS; McNair, Loor y Droppleman, 1971); la ***ira*** mediante la subescala de estado de la Escala de la Expresión de Ira Estado-Rasgo (STAXI-2; Spielberg, 1988) y la ***salud física percibida*** mediante un único ítem (“En la actualidad; ¿Cómo considera usted que es su salud?”). Igualmente, se

evaluó el ***deseo del cuidador de institucionalizar*** a su familiar, mediante un único ítem ("Durante la última semana; ¿En qué medida ha pensado en la posibilidad de ingresar a su familiar en una residencia?).

4.3 Análisis de datos

Si bien en cada uno de los cuatro trabajos que siguen a continuación se describen los análisis de datos específicos realizados para cada uno de ellos, a continuación se indican los análisis fundamentales que se han realizado para analizar los objetivos de esta investigación.

El análisis del papel moderador de los distintos factores de la autoeficacia en el proceso de estrés (Estudio 1) se llevó a cabo mediante **análisis de moderación** siguiendo el procedimiento recomendado por Baron y Kenny (1986). Así, se realizaron diferentes análisis de **regresión jerárquica** considerando las distintas dimensiones del modelo de estrés. Igualmente, con el objetivo de analizar el tipo de relación existente entre frecuencia de comportamientos problemáticos y carga, por un lado, y entre carga y depresión y ansiedad por el otro, se realizaron **pruebas de significación de moderación post-hoc** siguiendo el procedimiento recomendado por Holmbeck (2002).

Para analizar la estructura factorial de la Escala Justificaciones Culturales para el Cuidado-Revisada (Estudio 2) se realizó un **análisis factorial exploratorio** utilizando el método de extracción de componentes principales y aplicando la rotación varimax.

Para llevar a cabo los Estudios 2 y 3 se agrupó a la muestra en cuatro grupos de cuidadores en función de sus puntuaciones en las subdimensiones de motivos (extrínsecos e intrínsecos) para cuidar (Estudio 2) y la frecuencia y la satisfacción con la activación conductual (Estudio 3). Así, los cuidadores fueron divididos en función de sus puntuaciones (altas o bajas) en estas variables, basando dicha división en la mediana de

cada variable. Para analizar las diferencias entre los cuatro grupos en las distintas variables evaluadas se realizaron análisis de varianza (**ANOVA)** (en variables independientes individuales cuantitativas), análisis de varianza multivariado (**MANOVA)** (en variables independientes agrupadas cuantitativas) y **pruebas de independencia** Chi-Cuadrado (en variables categóricas).

En el Estudio 4, para analizar si las variaciones en las distintas variables moduladoras a lo largo del tiempo predecían significativamente los cambios en depresión, se realizaron **análisis de modelos generales lineales mixtos**.

Finalmente, con el objetivo de analizar la relación entre las distintas variables de los diferentes estudios se realizaron análisis de **correlaciones** bivariadas de Pearson. Todos estos análisis se realizarán mediante el programa estadístico SPSS, versión 17.0 (PASW).

1

ESTUDIO UNO

ANALYSIS OF THE MODERATING EFFECT OF SELF-EFFICACY DOMAINS IN DIFFERENT POINTS OF THE DEMENTIA CAREGIVING PROCESS

Romero-Moreno, R., Losada, A., Mausbach, B.T., Márquez-González, M., Patterson, T.L. and López, J.

Aging and Mental Health (en prensa)

5. Estudio Uno: Analysis of the moderating effect of self-efficacy domains in different points of the dementia caregiving process

5.1 Abstract

Introduction

Studies analyzing the moderator role of self-efficacy have centered their attention on the relationship between stressors and distress. However, drawing upon the stress and coping model, the moderator effects of self-efficacy may appear in the relationship between other key elements of the stress process.

Objectives and method

The purpose of this study was to analyze, in a sample of 167 dementia family caregivers, a) the moderating effect of self-efficacy for managing behavioural problems on the relationship between frequency of behavioural problems and burden; and b) the moderating effect of self-efficacy for controlling upsetting thoughts on the relationship between burden and caregivers' distress (depression and anxiety).

Results

While no support has been found for the hypothesis that self-efficacy for managing behavioural problems moderates the relationship between frequency of behavioural problems and burden, our findings support the moderator role of self-efficacy for controlling upsetting thoughts in the relationship between burden and distress. No differences in distress measures are found between caregivers with high and low scores on self-efficacy for controlling upsetting thoughts when they report low levels of burden. However, when the levels of burden are high, caregivers with high self-efficacy for controlling upsetting thoughts report significantly lower levels of distress than caregivers with low self-efficacy for controlling upsetting thoughts.

Conclusion

Self-efficacy for controlling upsetting thoughts may be particularly effective for caregivers who report high burden scores, attenuating the impact of burden on caregivers' distress (depression and anxiety).

Keywords: behavioural problems; burden; caregivers; dementia; distress; moderation.

5.2 Introduction

Research is consistent regarding the association between being a caregiver of people with dementia and having poorer psychological and physical health (Pinquart & Sörensen, 2003). Due to the considerable demands that dementia caregivers must face during a long time period, caring for relatives suffering dementia has been conceptualised as a chronic stressful situation (Vitaliano, Young & Zhang, 2004). Drawing upon the stress and coping model (Kim, Knight & Flynn-Longmire, 2007; Lazarus & Folkman, 1984; Pearlin, Mullan, Semple & Skaff, 1990), both objective caregiver stressors (such as care receiver frequency of behaviour problems or functional status) and subjective stressors (such as burden) have an impact on dementia caregivers' mental health (e.g., anxiety and depression). However, the effects of the stressors on caregiving outcomes vary among caregivers. Several variables such as social support or coping have been shown to have an influence in the impact that dementia caregiving has on caregivers (e.g., Gottlieb & Rooney, 2004; Schulz, O´Brien, Bookwala and Fleissner, 1995; Thompson, Futterman, Gallagher-Thompson, Rose & Lovett, 1993).

5.2.1 Caregiver self-efficacy: A multidimensional construct

Caregivers' self-efficacy is another variable that has been studied in the dementia caregiving research as a potential moderator in the relationship between stressors and distress, with research consistently showing the positive effects that this variable has on dementia caregivers' distress (Márquez-González, Losada, López & Peñacoba, 2009; Rabinowitz, Mausbach, Thompson & Gallagher-Thompson, 2007; Steffen, McKibbin, Zeiss, Gallagher-Thompson & Bandura, 2002).

Traditionally, self-efficacy has been defined as the conviction that one can successfully execute the behaviours required to produce certain outcomes (Bandura,

Adams & Beyer, 1977). In the dementia caregiving context, self-efficacy has been conceptualised as the belief in the ability to carry out different activities related to caregiving (Steffen *et al*., 2002). Researchers have highlighted the multidimensionality of self-efficacy, which means that it is not a global entity but varies across activity domains, task demands, and situational characteristics (Bandura, 1997; Steffen *et al*., 2002). Several dimensions have been described for caregiving self-efficacy. For example, Steffen *et al.* (2002) identified three dimensions that were termed self-efficacy for asking for help, for responding to disruptive patient behaviours, and for controlling upsetting thoughts. Fortinsky, Kercher and Burant (2002) included two self-efficacy domains for managing dementia, named symptom management and community support service use. Zeiss, Gallagher-Thompson, Lovens, Rose, & McKibbin (1999) developed two self-efficacy dimensions called self-care self-efficacy and caregiver problem-solving self-efficacy.

The multidimensionality of self-efficacy has been supported through studies that have found different patterns of association between some self-efficacy dimensions and other variables included in the caregiving stress process. For example, Steffen *et al.* (2002) found a positive association between self-efficacy for asking for help and social support, while also finding an inverse relationship between self-efficacy for managing disruptive problem behaviours and self-efficacy for controlling upsetting thoughts and caregivers' anger and anxiety respectively. Márquez-González *et al.* (2009) found that self-efficacy for asking for help and for controlling upsetting thoughts –but not for managing behavioural problems- had inverse relationships with dysfunctional thoughts about caregiving and caregivers depression. These results suggest that understanding each caregiver's profile of beliefs about their abilities to cope with different situations or aspects may help clinicians to identify areas of vulnerability in handling the myriad demands of a caregiving situation.

Additional support to the importance of considering caregivers' self-efficacy and, specifically, for considering its multidimensional nature, has been obtained through intervention studies. Moderator effects of self-efficacy dimensions have been found in the analysis of the efficacy of interventions for reducing caregivers' distress. While caregivers with high baseline scores on self-efficacy for obtaining respite obtain similar benefits from a telephone support group than from an in-home behavioural management program, caregivers with low baseline scores on this self-efficacy subscale seem to benefit only from an in-home behavioural management program (Gallagher-Thompson et al., 2007). Similarly, caregivers with low scores on self-efficacy for obtaining respite and self-efficacy for controlling upsetting thoughts benefited more from a psychoeducational intervention than those caregivers with low scores on these measures that participated in a support based group (Rabinowitz et al., 2006).

5.2.2 The moderator role of self-efficacy in the relationship between stressors and distress.

The moderator role of self-efficacy in the relationship between stressors and caregivers' distress has also been analyzed. Although Gilliam and Steffen (2006) found no moderation effect of self-efficacy in the relationship between care recipient´s cognitive impairment and behaviour problems and depression, Rabinowitz, Mausbach and Gallagher-Thompson (2009) found that self-efficacy for managing behavioural problems moderates the relationship between care recipient´s memory and behavioural problems and symptoms of depression. Specifically, they found that those caregivers with high self-efficacy for managing disruptive problem behaviours were less likely to experience depressive symptoms even when the frequency of disruptive behaviours was high (Rabinowitz *et al.,* 2009). These contradictory results may be due to between studies differences in the inclusion criteria. While reporting moderate distress (for example,

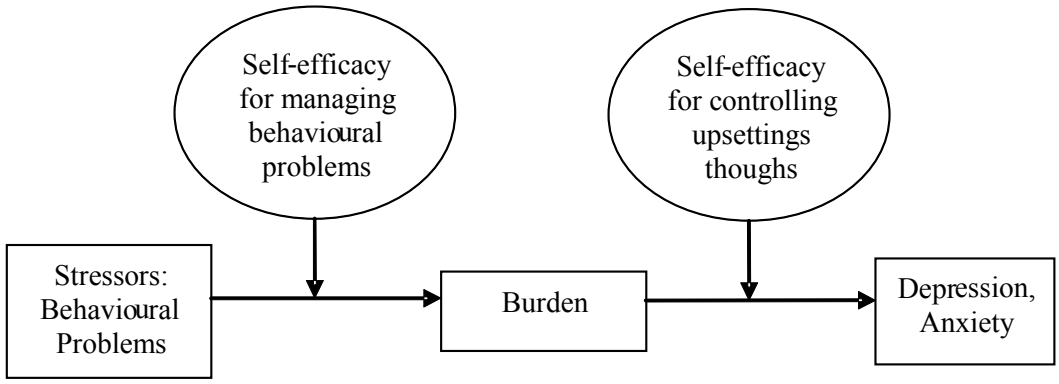
moderate depression levels and at least two weekly-occurring behavioral problems of the patient) was required for entering the study in the Gilliam and Steffen study (2006), in the Rabinowitz et al. study (2009) caregivers were included independently of their scores on stressors or distress.

The need for more studies that analyze the self-efficacy moderator effect, specifically considering other variables such as burden and anxiety, has been suggested (e.g., Rabinowitz *et al.,* 2009). Also, to our knowledge, studies analyzing the moderator role of self-efficacy have centered their attention in the relationship between objective stressors and distress. However, drawing upon the stress and coping model (e.g., Chun, Knight & Youn, 2007; Kim *et al.*, 2007), and considering the multidimensional nature of self-efficacy, the moderator effects of self-efficacy may appear in the relationship between other key elements of the stress process (Van Den Wijngaart, Vernooij-Dassen & Felling, 2007). Theoretically, it seems plausible that the effect of self-efficacy for managing behavioural problems (e.g., "when your relative forgets your daily routine and asks when lunch is right after you´ve eaten; how confident are you that you can answer him/her without raising your voice?") may be greater in the relationship between objective stressors and burden. On the contrary, the effects of self-efficacy for controlling upsetting thoughts (e.g., "how confident are you that you can think about unpleasant aspects of taking care of your relative?") may not have an influence on the association between objective stressors and burden but, once caregivers appraise stressors as burdensome, it may attenuate the effects of burden on distress.

Hence, different dimensions of self-efficacy may play their role at different points in the caregiving stress process. Taking into account these considerations, our hypotheses are: a) self-efficacy for managing behavioural problems moderates the relationship between behavioural problems and burden; and b) self-efficacy for controlling upsetting

thoughts moderates the relationship between burden and distress of the caregivers (depression and anxiety). Figure 5.1 illustrates these hypotheses in the frame of the caregiving stress model.

Figure 5. 1. Hypotheses about the moderator role of specific self-efficacy domains on the caregiving stress process.



5.3 Method

5.3.1 Participants

Participants in this study were 167 family caregivers of persons with dementia from Madrid (Spain). The inclusion criteria were similar to those reported in similar studies that have analyzed caregivers' self-efficacy (e.g., Fortinsky et al., 2002; Gallagher-Thompson et al., 2007; Gignac & Gottlieb, 1996) or that have be done in the framework of the stress and coping model (e.g., Kim & Knight, 2008). Caregivers' should identify themselves as the main source of help for their relatives, providing in-home care, having a minimum age of 18 years, devoting more than one hour per day to caregiving duties, and providing care for more than three consecutive months. The characteristics of the sample are shown in Table 5.1.

Table 5. 1. Sample characteristics (N = 167)

	n (%)	M (SD)	Scale Range
Caregiver gender			
Female	129 (77.20)		
Male	38 (22.80)		
Relationship			
Spouse	57 (34.30)		
Son/Daughter	100 (60.20)		
Other	10 (5.50)		
Caregiver age		59.88 (12.54)	29-87
Daily hours caring		11.51 (8.08)	1-24
Time caring (months)		53.35 (45.87)	4-312
Care recipient disease			
Alzheimer's Disease	93 (55.70)		
Other dementia	74 (44.30)		
Care recipient age		79.31 (8.64)	48-97

5.3.2 Procedure

Caregivers were contacted through different Social Services and Day Care centers from Madrid, which provided the necessary information in order to contact them (e.g., telephone and names), and through media announcements (e.g., Internet). In order to verify that caregivers met the inclusion criteria, caregivers first answered basic screening questions via an initial telephone call, which was followed by a detailed face-to-face interview that took place in their respective social and health centers.

5.3.3 Measures

a) Perceived Self-efficacy

Perceived self-efficacy, or the caregiver's perceptions of their confidence in coping effectively with different caregiving tasks, was measured using two subscales of the Revised Scale for Caregiving Self-efficacy (Steffen *et al*., 2002): self-efficacy for responding to disruptive patient behaviours and self-efficacy for controlling upsetting thoughts. Specifically, the Spanish version of the scale (Márquez-González *et al*., 2009) was used. The subscale of self-efficacy for responding to disruptive patient behaviours consists of five items assessing caregivers' confidence to respond to their relatives' problematic behaviours (i.e. "how confident are you that you, when … asks you four times in the first hour after lunch when lunch is, you can answer without raising your voice"). The subscale of self-efficacy for controlling upsetting thoughts consists of five items assessing the confidence that the caregiver has to be able to turn off or get rid of different type of negative thoughts (i.e. "how confident are you that you can control thinking about what you are missing or giving up because of caring"). In both subscales, the answers range from 0 to 100 (0 = "cannot do at all"; 100 = " certain can do").

b) Frequency of behavioural problems

The Revised Memory and Behaviour Problems Checklist (Teri *et al*., 1992) was used. It is a 24 item-measure that assess the frequency of behavioural problems in dementia patients (i.e., "during the past week; how often did your relative ask the same question over and over?"), with answers ranging from 0 = "not at all" to 4 = "extremely".

c) Functional status

Patients' functional status was measured using the Barthel Index (Mahoney and Barthel, 1965). Caregivers are queried on the 10-item scale that assesses the level of independence for Activities of Daily Living (ADL) (i.e., "what extent is your relative able to feed by her/himself?"). The answers range from 0 = "dependent" to 10 ="independent". Higher scores are indicative of higher level of independence in the patient.

d) Burden

Burden was assessed through the Zarit Burden Interview (Zarit, Reever, & Bach-Peterson, 1980). It consists of 22 Likert type items that measure how much discomfort is caused by situations related to different problem areas, such as the caregiver´s health, psychosocial well-being, finances, social life or the relationship between the caregiver and the care recipient (i.e. "I feel that my spouse makes requests which I perceive to be over and above what she/he needs"). The answers range from 0 = never to 4= always, and the 22 items are summed to create a total score ranging from 0 to 88.

e) Depression

Depressive symptomatology was assessed with the Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977). Although it was designed to evaluate depression in general population, it is one of the most used scales in caregiving research (Schulz *et al*., 1995). It consists of 20 Likert-type items that assess how much the person manifested depressive symptoms during the last week (i.e., "I felt that everything I did was an effort"). Answers range from 0 (hardly ever or never) to 3 (all the time).

f) Anxiety

Anxiety was assessed using the Tension Subscale of the Profile of Mood States (POMS; McNair, Loor & Droppleman, 1971). It consists of 9 Likert-type items that measure the levels of anxiety (i.e., "during last week, how often did you feel nervous?") of the caregivers, with answers ranging from 1 (not at all) to 5 (very much).

5.4 Statistical Analysis

Descriptive information (means, standard deviations, and ranges) of the variables of the study and correlations between them are shown in Table 5.2.

In order to test for moderation, we used Baron and Kenny's (1986) criteria. Hierarchical regression analyses were conducted based on the stress and coping model while controlling for other relevant variables. With the aim of reducing problems arising from multi-collinearity, all independent variables were centered at their means. Also, all interaction variables were created by multiplying the centered variables. First, we analyzed the moderation effect of self-efficacy for responding to disruptive patient behaviours in the relationship between frequency of behavioural problems and burden. In this case, burden was considered our dependent variable. In the first step, gender, age and the relationship between caregiver and care-recipient were introduced. In the second step, functional status was introduced. Frequency of behavioural problems was introduced in the third step, and self-efficacy for responding to disruptive patient behaviours and its interaction with frequency of behavioural problems were included in the fourth and last step.

Next, we analyzed the moderation effect of self-efficacy for controlling upsetting thoughts in the relationship between burden and caregivers' distress (depression and anxiety). In this case, we conducted two hierarchical regressions using as dependent

variables depression and anxiety. In both cases, gender, age and the relationship between caregiver and care-recipient were introduced in the first step. Functional status and frequency of behavioural problems were introduced in the second step. In the third step, burden was introduced and, finally, in the fourth step, self-efficacy for controlling upsetting thoughts and its interaction with burden were included. In addition, in order to determine the nature of the relationship between frequency of behavioural problems and burden on one hand, and burden and depression and anxiety on the other, for caregivers with high (+ 1SD) and low (- 1SD) self-efficacy, post-hoc analyses were used using the procedure described by Holmbeck (2002). For all these analyses the SPSS program (version 17.0) was used.

5.5 Results

5.5.1 Sample characteristics

As seen in Table 5.1, most of the caregivers were women and were caring for their parents. Participants were 59.88 years on average and had been caring for their relatives for more than four years.

5.5.2 Outliers, normality, multicollinearity and reliability

Following Tabachnick and Fidell (1996) criteria, we conducted analyses to test normal distribution of the variables, univariate and multivariate outliers. For all variables, neither univariate (z scores in excess of 3.29; $p < .001$) nor multivariate (Mahalanobis distance at $p < .001$) outliers were found. Skewness and kurtosis were within the expected values. Multicollinearity was tested and it did not appear to be a problem as the observed highest value of the variance inflation factors (VIFs) and the condition index (CI) were 1.31 and 11.83 for self-efficacy for responding to disruptive patient behaviours and

burden, respectively. The internal consistency (Cronbachs' alpha) for the different scales of the assessed variables were as follows: .80 and .82 for the self-efficacy for responding disruptive patient behaviours and for the self-efficacy for controlling upsetting thoughts subscales, respectively; .82 for the frequency of behavioural problems scale; .92 for the functional capacity scale; .90, for the burden scale; and .90 for both the depression and anxiety scales.

5.5.3 Correlational analysis

The analysis of correlations between the assessed variables (see Table 5.2) shows that, while both self-efficacy dimensions are significantly correlated with each other, only self-efficacy for responding to behavioural problems was associated with frequency of behavioural problems. On the contrary, only self-efficacy for controlling upsetting thoughts was significantly associated with depression: higher scores on self-efficacy for controlling upsetting thoughts were associated with lower depression scores. Both levels of burden and frequency of behavioural problems were associated with caregivers' distress (depression and anxiety).

Table 5. 2. Correlations, Means, Standard Deviations and Ranges of the assessed variables

	1	2	3	4	5	6	Mean	SD	Range
1. Functional capacity							66.67	32.10	0-100
2. Frequency of behavioural problems	-.16*						35.98	15.00	1-83
3. Burden	-.15	.32**					30.88	15.92	1-69
4. Self-efficacy	-.08	.21**	-.07				245.22	149.50	0-500

	1	2	3	4	5	6	Mean	SD	Range
for responding to disruptive patient behaviours									
5. Self-efficacy for controlling upsetting thoughts	-.16*	.01	-.00	.40**			279.91	147.07	0-500
6. Depression	-.10	.30**	.49**	-.09	-.22**		18.54	11.84	0-55
7. Anxiety	-.03	.30**	.52**	.04	-.12	.69**	16.77	9.14	0-36

(*p < 0.05; ** p < 0.01)

5.5.4 Relationship between frequency of behavioural problems, self-efficacy for responding behavioural problems and burden

The results of this regression analysis are shown in Table 5.3. Significant main effects on burden were found in the final model for caregiver gender, frequency of behavioural problems and self-efficacy for managing disruptive patient problems. However, moderation was not found, given that there was not a significant effect on burden for the frequency of behavioural problems-by-self-efficacy for responding to disruptive patient behaviours interaction.

Table 5. 3. Moderation analysis of the effect of self-efficacy for responding to disruptive patient behaviours in the relationship between frequency of behavioural problems and burden.

	Standard Betas and t scores							
	Step 1		Step 2		Step 3		Step 4	
	β	t	β	t	β	t	β	t
Caregiver gender	.18*	2.19	.18*	2.20	.20*	2.51	.19*	2.50

	Standard Betas and t scores							
(male = 0; female = 1)								
Caregiver age	-.08	-.75	-.10	-.99	-.01	-.09	-.00	-.01
Caregiver relationship (non-spouses = 0; spouses = 1)	-.06	-.52	-.03	-.27	-.02	-.16	-.03	-.27
Functional Capacity			-.16*	-2.07	-.11	-1.48	-.12	-1.64
Frequency of behavioural problems					.29**	3.61	.31**	3.92
Self-efficacy for responding to disruptive patient behaviours							-.18*	-2.34
Frequency of behavioural problems X self-efficacy for responding to disruptive patient behaviours							-.10	-1.26
R^2	.040		.060		.127		.151	
ΔR^2	.058		.025		.071		.033	

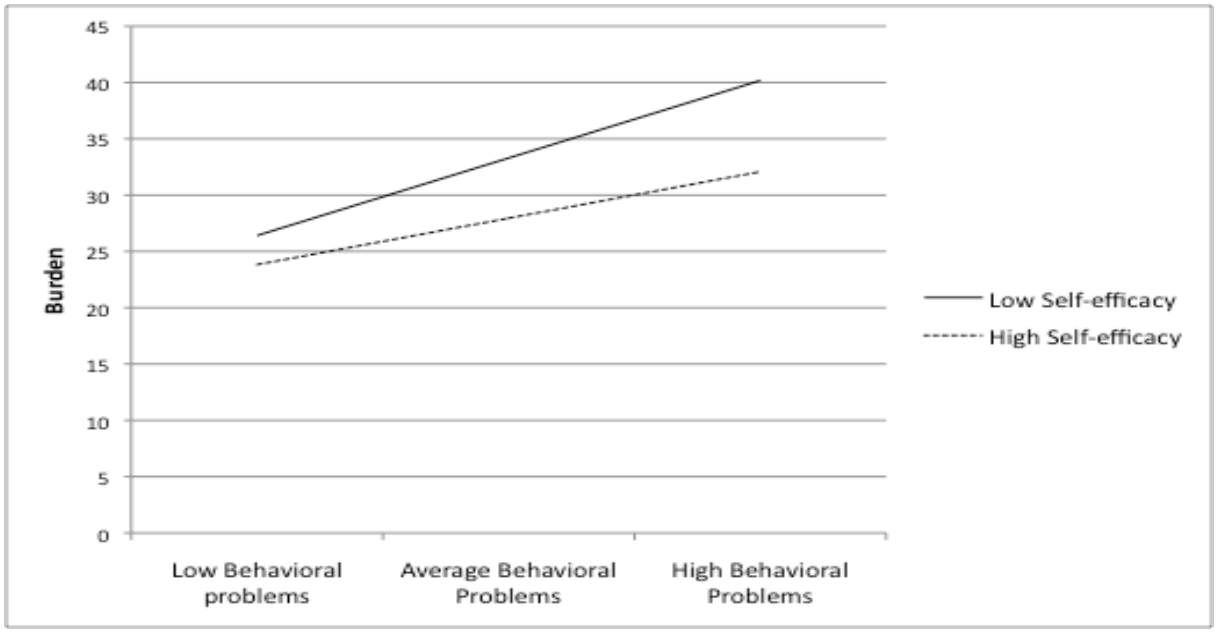
(*p < 0.05; ** p < 0.01)

Although no moderator effect of self-efficacy for managing disruptive patient problems was found, we conducted post-hoc analyses following the procedure described by Holmbeck (2002) for caregivers with high (+1 SD) self-efficacy versus low self-efficacy (-1 SD) in order to determine the nature of the relationship between frequency of behavioural problems and burden. Results of these analyses (see Figure 5.2) indicated that, when self-efficacy for responding to disruptive problems was low, the relationship between frequency of behavioural problems and burden was significant (B = .46; t = 4.30; p < .01). Specifically, when the frequency of behavioural problems was low, the mean

burden score was 26.41, compared to 40.18 when frequency of behaviour problems was high.

When self-efficacy was high, the relationship between frequency of behavioural problems and burden remained significant (B = .28; t = 2.41; p < .05). The range of scores on burden varied from a mean of 23.82 when the frequency of behavioural problems was low to 32.07 when it was high.

Figure 5. 2. Estimated relationship between frequency of behavioural problems and burden in participants with low (- 1SD) versus high (+ 1SD) self-efficacy for responding to disruptive problems.



5.5.5 Relationship between burden, self-efficacy for controlling upsetting thoughts and distress

As shown in Table 5.4, considering depression as dependent variable, a significant effect of frequency of behavioural problems, burden and self-efficacy for controlling upsetting thoughts was found in the final model. In addition to these main effects, the burden-by-self-efficacy for controlling upsetting thoughts interaction was also significant.

Table 5. 4. Moderation analysis of self-efficacy for controlling upsetting thoughts on the relationship between burden and depression.

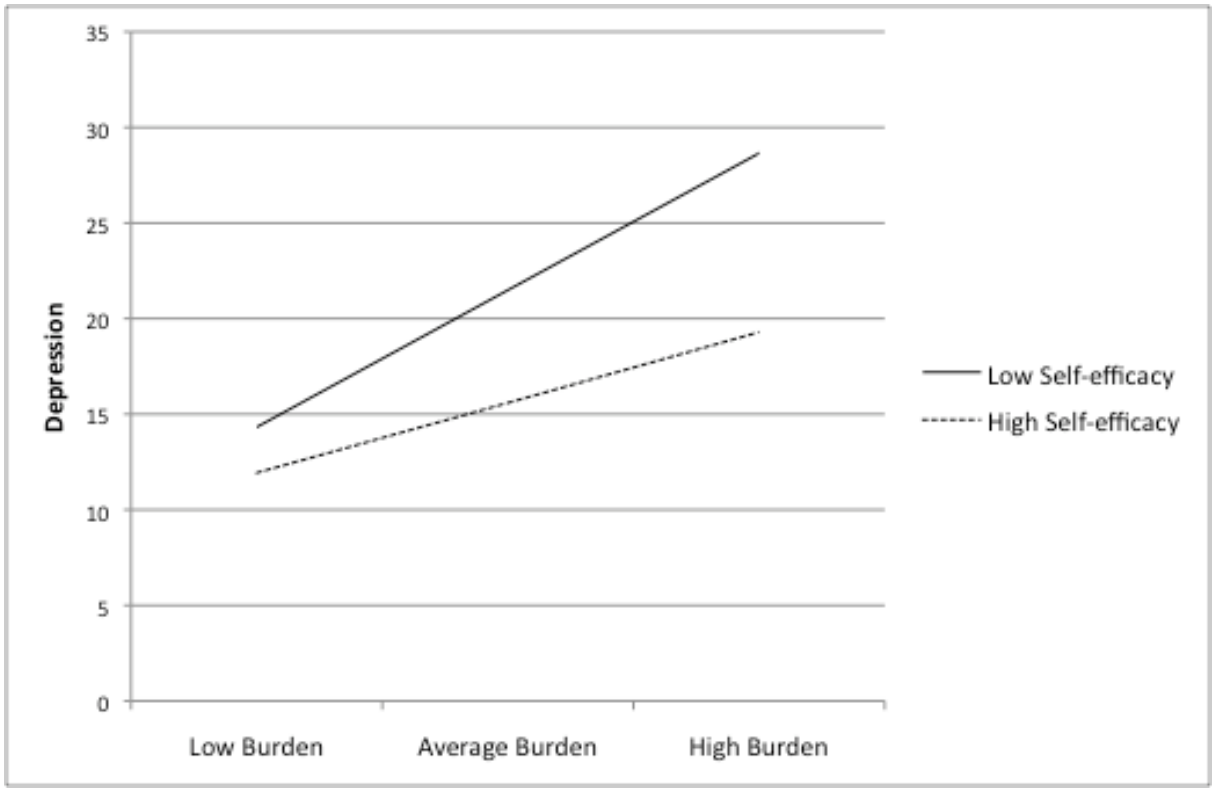
	Standard Betas and t scores							
	Step 1		**Step 2**		**Step 3**		**Step 4**	
	β	t	β	t	β	t	β	t
Caregiver gender (male = 0; female = 1)	.18*	2.19	.20*	2.53	.11	1.56	.09	1.27
Caregiver age	-.10	-.94	-.01	-.13	-.01	-.10	-.03	-.38
Caregiver relationship (non-spouses = 0; spouses = 1)	.07	.66	.10	.97	.11	1.16	.12	1.32
Functional Capacity			-.05	-.68	-.00	-.04	-.04	-.57
Frequency of behavioural problems			.32**	3.92	.19*	2.50	.17*	2.36
Burden					.44**	5.98	.44**	6.25
Self-efficacy for controlling upsetting thoughts							-.25**	3.65
Burden X Self-efficacy for controlling upsetting thoughts							-.14*	-2.06
R^2	.020		.107		.270		.328	
ΔR^2	.038		.097		.163		.064	

(*p < 0.05; ** p < 0.01)

The burden-by-self-efficacy for controlling upsetting thoughts interaction is shown in Figure 5.3. Results indicated that when self-efficacy for controlling upsetting thoughts was low, there was a significant relationship between burden and depression (B =.60; t =

7.37; $p < .01$), with mean scores on depression ranging from 14.32 when burden was low (-1 SD) to 28.65 when it was high (+1 SD). Although the relationship between burden and depression was still significant when self-efficacy for controlling upsetting thoughts was high ($B = .31$; $t = 3.00$; $p < .01$), the scores on depression varied from 11.93 when burden was low to 19.29 when it was high.

Figure 5. 3. Estimated relationship between burden and depression in participants with low (- 1SD) versus high (+ 1SD) self-efficacy for controlling upsetting thoughts.



As it is shown in Table 5.5, when we considered anxiety as the dependent variable, significant effects were found in the final model for caregiver gender, caregiver age, relationship between caregiver and care-recipient, frequency of behavioural problems, burden and self-efficacy for controlling upsetting thoughts. Also, the results showed a

significant effect of the interaction between burden and self-efficacy for controlling upsetting thoughts.

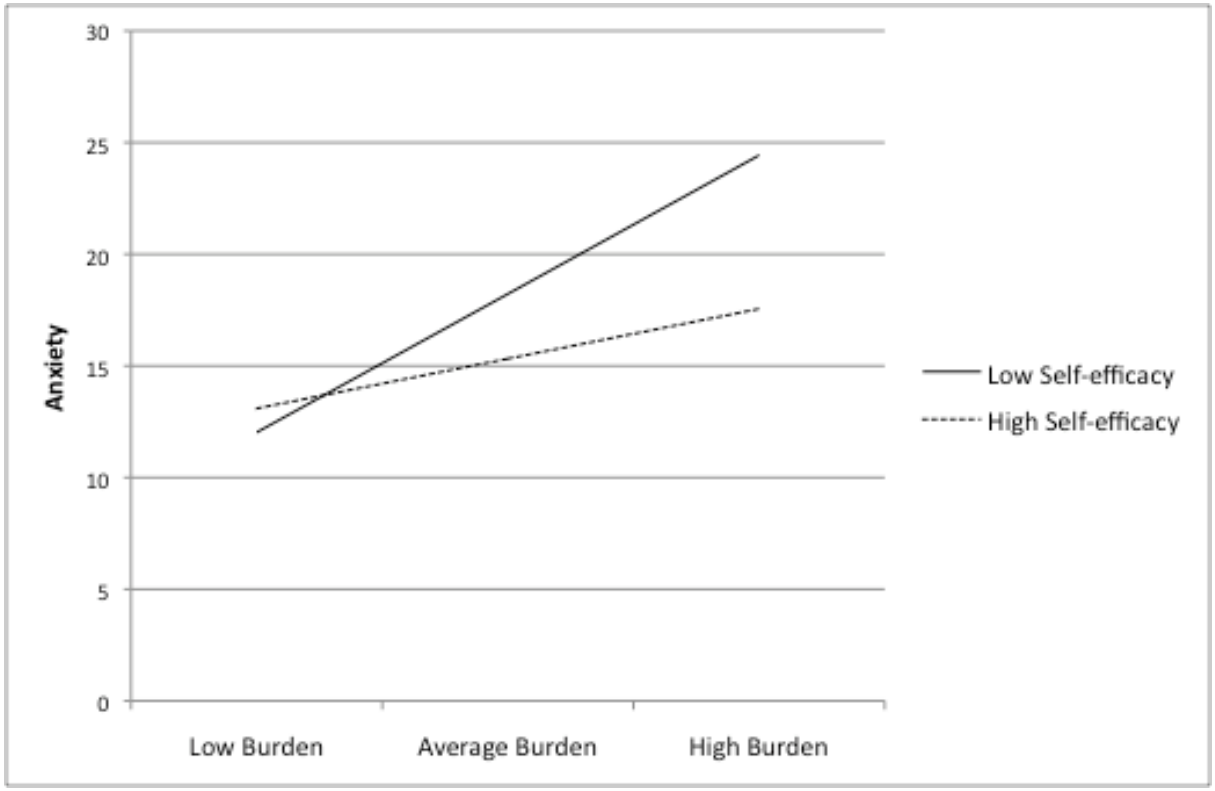
Table 5. 5. Moderation analysis of self-efficacy for controlling upsetting thoughts on the relationship between burden and anxiety.

	Standard Betas and t scores							
	Step 1		**Step 2**		**Step 3**		**Step 4**	
	β	**t**	**β**	**t**	**β**	**t**	**β**	**t**
Caregiver gender (male = 0; female = 1)	.25**	3.08	.26**	3.42	.17*	2.48	.16*	2.38
Caregiver age	-.27**	-2.67	-.18	-1.82	-.18*	-2.00	-.19*	-2.20
Caregiver relationship (non-spouses = 0; spouses = 1)	.20*	1.97	.22*	2.22	.23**	2.59	.23**	2.74
Functional Capacity			-.00	-.01	.05	.76	.03	.51
Frequency of behavioural problems			.29**	3.66	.16*	2.14	.14*	1.96
Burden					.46**	6.54	.47**	6.85
Self-efficacy for controlling upsetting thoughts							-.15*	-2.37
burdenX Self-efficacy for controlling upsetting thoughts							-.21**	-3.29
R^2	.084		.148		.329		.377	
ΔR^2	.101		.074		.179		.054	

(*p < 0.05; ** p < 0.01)

We charted the burden-by-self-efficacy for controlling upsetting thoughts interaction in Figure 5.4. The results indicated that, when self-efficacy for controlling upsetting thoughts was low, the relationship between burden and anxiety was significant (B =68; t = 8.40; p < .01), with scores on anxiety ranging from 12.02 when burden was low to 24.43 when it was high. The relationship between burden an anxiety when self-efficacy was high remained significant (B = .25; t = 8.40; p < .01), with the scores on anxiety varying from 13.09 when burden was low to 17.55 when it was high.

Figure 5. 4. Estimated relationship between burden and anxiety in participants with low (- 1SD) versus high (+ 1SD) self-efficacy for controlling upsetting thoughts.



5.6 Discussion

Consistently with previous research on dementia caregiving (Gaugler, Kane, Kane & Newcomer, 2005; Hooker *et al*, 2002; Teri, 1997), the present study has found that

caregivers' reported frequency of behavioural problems are significantly associated with subjective stressors (burden) and negative outcomes (depression and anxiety). The stress and coping model (e.g., Haley, Levine, Brown & Bartolucci, 1987) hypothesizes that caregivers' self-efficacy may influence the relationship between stressors and outcomes. Drawing upon this model, this study examined the moderating effect of two self-efficacy domains in different points of the caregiving process: a) self-efficacy for managing behavioural problems in the relationship between behavioural problems and burden; and b) self-efficacy for controlling upsetting thoughts in the relationship between burden and distress (depression and anxiety).

In contrast with our hypothesis, the results do not support that self-efficacy for managing behavioural problems moderates the relationship between frequency of behavioural problems and caregiver burden. However, perceived self-efficacy for managing behavioural problems clearly benefits caregivers who report both low and high frequency of behavioural problems (Figure 5.2), suggesting that high self-efficacy for managing behaviour problems acts as a potential resource factor against dementia caregivers' levels of burden. That is, while greater exposure to behaviour problems was significantly related to higher reports of burden, higher self-efficacy for managing disruptive behaviours was also significantly associated with lower levels of burden, indicating this form of self-efficacy serves as a resource regardless of the level of stress experienced by the caregiver (Rose, Holmbeck, Coakley & Franks, 2004). However, these results should be interpreted with caution given the cross-sectional nature of the study. In this sense, it would be appropriate designing longitudinal and experimental studies in order to test the direction of the relationships.

Regarding self-efficacy for controlling upsetting thoughts, a negative relationship between this dimension and caregiver depression was found, in a similar way as it has

been found by other authors (e.g., Rabinowitz *et al.,* 2009). Our study adds to previous research showing that self-efficacy for controlling upsetting thoughts attenuates the impact that burden has on dementia caregivers' distress, suggesting a moderator (or protective) effect of this dimension in the relationship between dementia caregivers' burden and distress (for both depression and anxiety). This way, caregivers with high levels of burden and high levels of self-efficacy for controlling upsetting thoughts have less depression and anxiety, as compared with those caregivers with high levels of burden and low levels of self-efficacy. Self-efficacy for controlling upsetting thoughts may attenuate the impact that burden has on caregiver distress because it may be associated with cognitive and affective mechanisms leading to effective emotion regulation and behaviour modification strategies (Bandura, 1997). The perception of self-efficacy for controlling upsetting thoughts may thus be the result of the implementation of healthy self-regulation strategies on the part of caregivers, which help them to manage their automatic dysfunctional thoughts in ways that attenuate their impact on caregivers´ emotional well-being. Again, considering the cross-sectional nature of the study, results must be interpreted with caution. Although the directions of the associations between variables suggested by the stress and coping model have received empirical support (Chun et al, 2007; Haley et al, 1987), alternative explanations to the directions hypothesized in this study (for example, influences of the outcomes on caregivers' burden and on coping strategies; Pearlin et al, 1990; Schoenmakers, Buntinx & De Lepeire, 2009) could be possible. Longitudinal and experimentally designed studies are needed for advancing in this regard.

This study presents some limitations. First, the convenience nature of the sample does not allow us to generalize the results to the general caregiving population, as it consists of voluntary caregivers recruited through different health and social centers.

Services use is more prevalent among caregivers with stronger support networks (Lamura et al., 2008). Those caregivers who access these services may have more adaptative coping strategies (such us for help seeking behaviour) than other caregivers who do not use them. Also, the nature of the study is cross sectional, and both longitudinal and experimental data on the effect of the different domains of self-efficacy on caregiver distress are needed in order to be able to make any conclusion about causal mechanisms. Considering that a little over time stability of caregivers' self-efficacy has been found (Gignac & Gottlieb, 1996), and that caregivers' scores on burden or depression may change over time (although stable patterns of distress are found for the majority of caregivers; e.g., Li, Seltzer, & Greenberg, 1999; Schulz & Williamson, 1991), the moderator effect of self-efficacy on the caregivers' stress process should be confirmed longitudinally.

Another potential limitation of this study is related to the operationalization of the self-efficacy subscales. Due to the complexity of the scale, it has been recommended that the scale should be administered by an interviewer (Steffen et al., 2002). According to the authors of the scale, "caregivers may have difficulty understanding the nature of the Controlling Upsetting Thoughts subscale and resort to rating the frequency of negative cognitions rather than their ability to control them" (Steffen et al., 2002; p. 83). We belief that special attention should be paid to this subscale, given that self-efficacy for controlling upsetting thoughts is related with internal events (thoughts) which may be perceived by caregivers as of a higher abstract and complex nature when compared with other dimensions such as disruptive behaviors. In this sense, although, as Rabinowitz *et al.* (2009) suggests that caregivers with high self-efficacy for controlling upsetting thoughts may be proficient at managing negative cognitions and, consequently, reducing distress, it may not be clear what caregivers exactly understand and answer when they are asked

about the control of their thoughts. For example, some caregivers may not have thoughts that interfere in their lives, and, consequently, they may believe that they do have control of their upsetting thoughts. In a similar way, other caregivers may think that they control their thoughts, although they use dysfunctional strategies such as avoidance techniques. Further studies which identify and analyze the specific strategies involved in caregivers' "control of their upsetting thoughts" are clearly needed. Finally, it would be appropriate that future research analyze the moderator role of self-efficacy considering additional sources of objective stress such as patients' cognitive status, given the relationship of this variable with caregivers' health (e.g., Pinquart & Sörensen, 2007).

This study suggests that self-efficacy, both for responding to disruptive patient behaviours and for controlling upsetting thoughts, has positive consequences for caregivers' distress. In addition, the results of this study support the multidimensionality of the self-efficacy construct (Bandura, 2006; Steffen *et al.,* 2002), and suggests that different self-efficacy dimensions play different roles in the stress process: self-efficacy for responding to disruptive behaviours seems to be a resource against caregiver burden, regardless of the number of problem behaviours exhibited by their loved ones. On the other hand, self-efficacy for controlling upsetting thoughts seems to moderate the effects of burden on distress. The potential implications of these findings for caregiver interventions are twofold. First, because increased self-efficacy for managing disruptive behaviours serves as a resource factor, teaching caregivers skills for managing disruptive behaviours may be helpful for reducing burden in all caregivers, regardless of how disruptive their loved ones are. Second, because self-efficacy for controlling upsetting thoughts moderated the relationship between burden and distress (e.g., depression and anxiety), it appears teaching them skills to control their upsetting thoughts would be particularly useful for caregivers currently experiencing high levels of burden (as opposed

to low levels of burden). It should be noted that studies have found that treatments that promote changes in self-efficacy are indeed useful for reducing caregiver distress (Coon, Thompson, Steffen, Sorocco & Gallagher-Thompson, 2003). Hence, depending on the results of caregivers assessment, it may be useful to train them in behaviour techniques for managing disruptive behaviours (e.g., Teri, McCurry, Logsdon & Gibbons, 2005), to train them to manage upsetting thoughts (e.g., Márquez-González *et al*., 2007), or to train them in those areas in which they do not feel to be efficient.

5.7 References

Bandura, A. (1997). *Self-efficacy: the exercise of control*. New York: W.H. Freeman.

Bandura, A. (2006). Guide for constructing self-efficacy scales. In F. Pajares & T. 295 Urdan (Eds.), Adolescence and education, Volume 5 in the Adolescence and Education series (pp. 307–337). Greenwich, CT: Information Age Publishing.

Bandura, A., Adams, W.E., & Beyer, J. (1977). Cognitive processes mediating behavioral change. *Journal of Personality and Social Psychology, 35*, 125-135.

Baron, R.M., & Kenny, D.A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51*, 1173-1182.

Coon, D.W., Thompson, L., Steffen, A., Sorocco, K., & Gallagher-Thompson, D. (2003). Anger and depression management: Psychoeducational skill training interventions for women caregivers of a relative with dementia. *The Gerontologist, 43*,678–689.

Chun, M., Knight, B.G., & Youn, G. (2007). Differences in stress and coping models of emotional distress among Korean, Korean-American and White-American caregivers. *Aging and Mental Health, 11*, 20-29.

Fortinsky, R.H., Kercher, K., & Burant, C.J. (2002). Measurement and correlates of family caregiver self-efficacy for managing dementia. *Aging & Mental Health, 6*,153–160.

Gallagher-Thompson, D., Gray, H.L., Tang, P.C.Y., Pu, C.Y., Leung, L.Y.L., Wang, P.C., et al. (2007). Impact of In-Home behavioural management versus telephone

support to reduce depressive symptoms and perceived stress in Chinese caregivers: results of a pilot study. *American Journal of Geriatric Psychiatry 15*, 425–434.

Gaugler, J.E., Kane, R.L., Kane, R.A., & Newcomer, R. (2005). The longitudinal effects of early behavior problems in the dementia caregiving career. *Psychology and Aging, 20,* 100-116.

Gignac, M.A.M., & Gottlieb, B.H. (1996).Caregivers´ appraisals of efficacy in coping with dementia. *Psychology and Aging, 11,* 214-225.

Gilliam, C. M., & Steffen, A. M. (2006). The relationship between caregiving self-efficacy and depressive symptoms in dementia family caregivers. *Aging and Mental Health, 10*, 79–86.

Gotlieb, B.H., & Rooney, J.A. (2004). Coping effectiveness: Determinants and relevance to the mental health and affect of family caregivers of persons with dementia. *Aging and Mental Health, 8*, 364-373.

Haley, W.E., Levine, E.G., Brown, L., & Bartolucci, A.A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging, 2,* 323-330.

Holmbeck, G. N. (2002). Post-hoc probing of significant moderational and mediational effects in studies of pediatric populations. *Journal of Pediatric Psychology, 27,* 87–96.

Hooker, K., Bowman, S.R., Coehlo, D.P., Lim, S.R., Kaye, J., Guariglia, R., & Li, F. (2002). Behavioral change in persons with dementia: Relationships with mental and physical health of caregivers. *Journals of Gerontology: Psychological Sciences and Social Sciences, 57B*, 453-460.

Kim, J.H., & Knight, B.G. (2008). Effects of caregiver status, coping styles, and social support on the physical health of Korean American caregivers. *The Gerontologist, 48*, 287-299.

Kim, J., Knight, B.G., & Flynn-Longmire, C.V. (2007). The role of familism in stress and coping processes among African American and White dementia caregivers: Effects on mental and physical health. *Health Psychology, 26*, 564-576.

Lamura, G., Mnich E., Nolan, M., Wojszel, B., Krevers B., Mestheneos, L., & Döhner, H. (2008). Family carers´experiences using support services in Europe: empirical evidence from the EUROFAMCARE Study. *The Gerontologist, 48,* 752-771.

Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer Publishing Company.

Li, L.W., Seltzer, M.M., & Greenberg, J.S. (1999). Change in depressive symptoms among daughter caregivers: an 18-month longitudinal study. *Psychology and Aging, 14,* 206-219.

Mahoney, F.L., & Barthel, D.W. (1965) Functional evaluation: The Barthel Index. *State Journal, 4,* 61-65.

Márquez-González, M., Losada, A., Izal, M., Pérez-Rojo, G., & Montorio, I. (2007). Modification of dysfunctional thoughts about caregiving in dementia family caregivers: description and outcomes of an intervention programme. *Aging and Mental Health, 11*, 616-625.

Márquez-González, M., Losada, A., López, J., & Peñacoba, C. (2009). Reliability and Validity of the Spanish Version of the Revised Scale for Caregiving Self-Efficacy. *Clinical Gerontologist, 32*, 1–11.

McNair, D., Lorr, M., & Droppleman,L. (1971). *Profile of Mood States. Manual*. San Diego: Educational and Industrial Testing Service.

Pearlin, L.I., Mullan, J.T., Semple, S.J., & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30,* 583-594.

Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging 18*, 250-267.

Pinquart, M., & Sörensen, S. (2007). Correlates of physical health of informal caregivers: a meta-analysis. *Journal of Gerontology: Psychological Sciences, 62*, 126-137.

Rabinowitz, Y.G., Mausbach, B.T., Coon, D.W., Depp, C., Thompson, L.W., & Gallagher-Thompson, D. (2006). The moderating effect of self-efficacy on intervention response in women family caregivers of older adults with dementia. American Journal of *Geriatric Psychiatry, 14*, 642–649.

Rabinowitz, Y.G., Mausbach, B.T., & Gallagher-Thompson, D. (2009). Self-efficacy as a moderator of the relationship between care recipient memory and behavioral problems and caregiver depression in female dementia caregivers. *Alzheimer Disease and Associated Disorders, 23*, 389-394.

Rabinowitz, Y.G., Mausbach, B.T., Thompson, L.W., & Gallagher-Thompson, D. (2007). The relationship between self-efficacy and cumulative health risk associated with health behavior patterns in female caregivers of elderly relatives with Alzheimer´s dementia. *Journal of Aging and Health, 19*, 946-964.

Radloff, L.S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1,* 385-401.

Rose, B.M., Holmbeck, G.N., Coakley, R.M., & Franks, E.A. (2004). Mediator and moderator effects in developmental and behavioral pediatric research. *Developmental and Behavioral Pediatrics, 25*, 58-67.

Schoenmakers, B., Buntinx, F., & De Lepeleire, J. (2009). The relation between care giving and the mental health of caregivers of demented relatives: A cross-sectional study. *European Journal of General Practice, 15,* 99-106.

Schulz, R., O´Brien, A.T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist, 35*, 771-791.

Schulz, R., & Williamson, G.M. (1991). A 2-year longitudinal study of depression among Alzheimer's caregivers. *Psychology and Aging, 6*, 569-578.

Steffen, A.M., McKibbin, C., Zeiss, A.M., Gallagher-Thompson, D., & Bandura, A. (2002). The Revised Scale for Caregiving Self-Efficacy: Reliability and Validity Studies. *Journal of Gerontology: Psychological Sciences 57,* 74–86.

Tabachnick, B.G., & Fidell, L.S. (1996). *Using multivariate statistics* (3rd ed.). New York: Harper Collins.

Teri, L. (1997). Behavior and caregiver burden: behavioral problems in patients with Alzheimer disease and its association with caregiver distress. *Alzheimer Disease and Associated Disorders, 11*, 35-38.

Teri, L., McCurry, S.M., Logsdon, R., & Gibbons, L.E. (2005). Training community consultants to help family members improve dementia care: a randomized controlled trial. *The Gerontologist, 45*, 802-811.

Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., &Vitaliano, P.P. (1992). Assessment of Behavioral Problems in Dementia: The Revised Memory and Behavior Problems Checklist. *Psychology and Aging, 7,* 622-631.

Thompson, E.J., Futterman, A.M., Gallagher-Thompson, D., Rose, J.M., & Lovett, S.B. (1993). Social support and caregiving burden in family caregivers of frail elders. *Journal of Gerontology, 48*, 245-254.

Van Den Wijngaart, M.A, Vernooij-Dassen, M.J., & Felling, A.J. (2007). The influence of stressors, appraisal and personal conditions on the burden of spousal caregivers of persons with dementia. *Aging and Mental Health, 11*, 626-636.

Vitaliano, P.P., Young, H.M., & Zhang, J. (2004). Is caregiving a risk factor for illness? *Current Directions in Psychological Science, 13*, 13-16.

Zarit, S.H., Reever, R., & Bach-Peterson, J. (1980). Relatives of impaired elderly: Correlates of feelings of burden. *The Gerontologist, 20,* 649, 655.

Zeiss, A.M., Gallagher-Thompson, D., Lovens, S., Rose, J., & McKibbin C. (1999). Self-Efficacy as a Mediator of Caregiver Coping: Development and Testing of an Assessment Model. *Journal of Clinical Geropsychology, 5*, 221-230.

2

ESTUDIO DOS

MOTIVES FOR CARING: RELATIONSHIP TO STRESS AND COPING DIMENSIONS

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International Psychogeriatrics (en prensa)

6. Estudio Dos: Motives for caring: Relationship to stress and coping dimensions

6.1 Abstract

Background

Although research has highlighted the importance of including cultural factors in the analysis of caregiver stress, little is known about the effects of motives for caregiving on the stress and coping process. This study is aimed at analyzing the dimensional structure of the Cultural Justifications for Caregiving Scale- Revised (CJCS-R), and the effects of motives for caregiving on stressors, caregiver resources and outcome variables.

Methods

Dementia caregivers (N = 166) were interviewed. The following variables were assessed: motives for caregiving (CJCS-R), stressors (frequency of behavioural problems), resources (rumination, cognitive reappraisal), and outcomes (depression, anxiety and anger).

Results

A bidimensional structure was obtained for the CJCS-R, and the two factors were labelled Intrinsic and Extrinsic motives for caregiving. Participants were divided into four groups corresponding to four motivation profiles: HIHE = High Intrinsic Motives + High Extrinsic motives; LILE = Low Intrinsic Motives + Low Extrinsic Motives; HILE = High Intrinsic Motives + Low Extrinsic Motives; and LIHE = Low Intrinsic Motives + High Extrinsic Motives. No differences between groups were found in frequency of behavioural problems. Caregivers in the LIHE group had significantly worse consequences on caregiver resources and outcome variables compared to the other groups.

Conclusions

The results support the usefulness of considering motives for caregiving as a multidimensional construct. Analyzing caregivers' motivation profile may constitute a useful strategy for identifying caregivers at risk. Caregivers scoring simultaneously low on intrinsic motives and high on extrinsic motives may be at particular risk for negative caregiving outcomes.

Keywords: Dementia caregivers, culture, behavioural problems, rumination, cognitive reappraisal, anxiety, depression, anger.

6.2 Introduction

6.2.1 The Sociocultural Stress and Coping Model

Research shows that providing care to family members with dementia is associated with negative effects on physical and psychological health for caregivers (Pinquart & Sörensen, 2003). Considering that dementia caregiving has been described as a chronic stressor (Vitaliano, Young & Zhang, 2004), it is not surprising that the theoretical framework most commonly used in caregiving literature is the stress and coping model adapted to caregiving (Haley, Levine, Brown & Bartolucci, 1987). According to this model, the impact of stressors (such as care recipients' behavioural problems) on caregivers' health outcomes (such as depression and anxiety) may be attenuated or reinforced by resource variables (such as coping strategies). One of these resource variables is the repertoire of strategies which caregivers use to cope with their emotions (emotion regulation strategies). In this regard, research has shown how the use of maladaptive emotion regulation strategies – such as low acceptance or low positive reframing – significantly predicts higher levels of caregiver distress (Cooper, Katona, Orrel & Livingston, 2008).

In addition to the dimensions of the stress and coping model referred to above, research has provided support for the inclusion of cultural factors in the model (e.g., Pinquart & Sörensen, 2005). The addition of cultural variables to the model has led to the development of the sociocultural stress and coping model (Knight & Sayegh, 2010). This model highlights the importance of analyzing the influence that cultural values have on a common core model shared by different cultural groups that considers that caregiving distress is due to the appraisal of caregiving stressors as burdensome (Knight & Sayegh, 2010). The main way in which cultural values (e.g. obligation values) have an impact on

caregiver outcomes is via its influence on caregivers' resources (e.g. use of coping strategies and social support) (Knight & Sayegh, 2010).

Even though the importance of cultural factors in the caregiving process has been highlighted by the literature, most of the studies that have focused on their analysis have used non-theoretical approaches or have analyzed group membership (rather than specific cultural variables) as the only criterion for explaining cultural differences in caregiving (Dilworth-Anderson, Williams & Gibson, 2002; Knight & Sayegh, 2010; Knight, Silverstein, McCallum & Fox, 2000).

6.2.2 Motivation for caregiving

Among the cultural variables studied in the caregiving literature are the motives for caregiving. This variable has been defined as the expressions and meanings, derived from culture, that direct particular behaviours, such as the provision of care to older dependent relatives and their families (Dilworth-Anderson *et al.*, 2005). Dilworth-Anderson, Goodwin and Williams (2004) considered motives for caregiving as a resource, suggesting that they are related to beliefs and attitudes about caring that encourage the use of coping strategies to deal with stressors in the caregiving situation.

Different procedures have been used to assess motivation for caregiving, though most of them have either failed to use validated measures or have used qualitative methodology (e.g., Hsu & Shyu, 2003). However, qualitative research has contributed to our understanding of the impact of motivations for caring on caregiver's distress by helping to identify caregiving motives as a first step for creating measures to assess them, as well as finding evidence suggesting that motives to provide care are culture-specific and may change over time (Hsu & Shyu, 2003; Quinn, Clare, & Woods, 2010). Some researchers have analyzed motives for caregiving by developing specific questions about

motives (e.g. "to what extent do you think you assist your mother because you feel obligated do so?) (Walker, Pratt, Shin & Jones, 1990). Walker *et al.*, 1990) or by inferring motives from particular caregiving characteristics, such as living close to the care recipient, which has been interpreted as a sign of caring by default or because there are no other viable choices (Campbell & Martin-Mathews, 2003). Also, specific instruments have been developed for assessing motives for caregiving. For example, Carruth (1996) created the Motivating Factors Index, composed of two factors, which were labelled "care motivated by obligatory feelings" (e.g. duty or avoid feelings of guilt) and "family loyalty/commitment" (e.g. want to show love). Kabitsi and Powers (2002) developed the Spousal Motivations of Care Inventory. This scale includes two sections, an open-ended question ("why do you provide the care of your spouse?") and an 18-item scale divided into six subscales examining cultural and personal beliefs about different motivations for care (love, gratitude, duty, religious beliefs and family harmony) (e.g., "It is my responsibility as a married person to provide care of my spouse"). Low internal consistency indexes (Cronbach's alpha) were reported in both studies and the scale developed by Kabitsi and Powers (2002) was specifically designed for spousal caregivers.

More recently, Dilworth-Anderson *et al.* (2004) developed the Cultural Justifications for Caregiving Scale (CJCS) for "assessing a relatively homogeneous construct of reasons for caregiving" (Dilworth-Anderson *et al.*, 2005; p. 259). This scale showed appropriate psychometric properties and a unidimensional factor structure in a sample of dementia caregivers, suggesting that higher scores on the scale represent stronger cultural reasons for giving care (Dilworth-Anderson *et al.*, 2005). In a study carried out in Spain with a representative sample of caregivers of adults older than 65 years old (IMSERSO, 2005), similar motives to those pointed out in the Dilworth-Anderson *et al.* (2005) scale were found (e.g., giving care due to religious beliefs or

because it is the caregiver's duty). However, in that IMSERSO (2005) study, 50.7% of the caregivers interviewed (N = 1504) reported that they provided care for a motive that was not tapped by the CJCS: "because they had no alternative" (IMSERSO, 2005; p. 49). Although there may exist differences between both studies in the types of motivations due to sample differences (dementia caregivers in the Dilworth *et al.* (2005) study and a mixed sample of caregivers of relatives with dementia and other disorders in the IMSERSO (2005) study), no differences in motivations for caring between dementia caregivers and non-dementia caregivers were found in the Carruth (1996) study. Research on motives for caregiving has also suggested that caregivers may have different types of motivations for caring; in other words, motives may not be mutually incompatible (Kabitsi & Powers, 2002; Walker *et al.*, 1990), and different profiles of motivations may exist between caregivers.

6.2.3 Motivation for caregiving and caregiver distress

Regarding the relationship between motives for caregiving and caregiver distress, Dilworth-Anderson, Williams and Cooper (1999) found no significant associations between these variables. However, in a more recent longitudinal study, they reported that having either very weak or very strong cultural justifications for caregiving predicted poor perceived psychological health over time (Dilworth-Anderson *et al.*, 2004). Having strong cultural justifications was interpreted in terms of duty and obligation, and having weak cultural justifications was interpreted in terms of necessity (unavailable additional resources of help) (Dilworth-Anderson *et al.,* 2004).

Support for associations between different motives for caregiving and caregiver distress has been also reported. In this sense, Cicirelli (1993) found that while caregivers with stronger obligation motives for caring reported greater burden, those with stronger

attachment motives reported significantly lower levels of burden. Similar results were reported by Lyonette and Yardley (2003): while motivations related to external pressures to care (i.e., guilt or the older person's expectation of care) predicted significantly greater caregiver stress, those related to internal desires to adopt the caring role (i.e., living up to one's principles or caring nature) were significant predictors of carer satisfaction. An association between obligations to provide care and caregiver's perceived stress and depression has also been found (Losada *et al.*, 2010).

In summary, the literature analyzing motives for caregiving has received little attention, and much less than would be expected considering the validated measurement instruments available and their influence on the caregiver stress and coping process. Considering that cultural factors can influence motivations to care (Quinn *et al.*, 2010), and that differences between cultures have been reported in the dimensional structure of cultural variables (e.g., familism) (Knight and Sayegh, 2010), the purpose of the present study is twofold: a) to analyze the dimensional structure of the Cultural Justifications for Caregiving Scale-Revised (CJCS-R); and b) to analyze the effect of motives for caregiving on the different dimensions making up the stress and coping model: stressors, caregiver resources and outcomes. Considering the Dilworth-Anderson *et al.* (2004, 2005) results, we expect to find data supporting a unidimensional structure of the CJCS-R and significant associations between scores, suggesting that care is provided due to obligation/duty or due to necessity and that caregivers having weak or strong scores on the CJCS-R will use poor emotion regulation strategies (e.g., rumination) and experience distress (e.g., depression).

6.3 Methods

6.3.1 Participants

Participants in this study were 166 family dementia caregivers living in the community. Inclusion criteria were: age 18 or over, identifying oneself as the main source of help for their relatives, and devoting at least one hour per day to caregiving tasks for a minimum period of 3 months. Sociodemographic characteristics of the sample (caregiver's age, relationship with care recipient, care recipient's age, time since caring began, hours spent caring per day, and care recipient's illness) are shown in Table 6.1.

Table 6. 1. Sociodemographic characteristics of the sample.

	N = 166
Gender (%)	
Female	78.30
Male	21.70
Relationship to care recipient (%)	
Spouse	35.50
Son/Daughter	58.40
Other (e.g., parent-in-law)	6.10
Caregiver's age	
Mean	59.46
SD	12.27
Range	29-84
Time since caring began (months)	
Mean	54.39
SD	46.54
Range	4-312
Hours caring per day	
Mean	11.00
SD	7.62

	N = 166
Range	1-24
Care recipient's illness (%)	
Alzheimer's Disease	61.40
Other dementia	38.60
Care recipient's age	
Mean	79.23
SD	8.35
Range	48-97

6.3.2 Procedure

Participants were recruited via various Health and Social Centres in Madrid and through announcements in the media. Initial contact was made by telephone to check whether caregivers matched the inclusion criteria. Face-to-face interviews were carried out at the centres involved. All participants gave informed consent to take part in the study, which was approved by the Spanish Ministry of Education and the Ethical Committee of the Rey Juan Carlos University (Madrid).

6.3.3 Variables and instruments

In addition to the sociodemographic variables, and drawing upon the socio-cultural stress and coping model of caregiving, the following variables were assessed:

a) Culture

Cultural motives for caregiving. Cultural motives for caregiving were assessed using the Cultural Justifications for Caregiving Scale (Dilworth-Anderson *et al.*, 2004). Considering the above-mentioned study from the IMSERSO (2005), in which a significant

percentage of caregivers (50.7%) reported that they provided care because "they had no alternative", we added the item "I provide care because I have no alternative", resulting in the Cultural Justifications for Caregiving Scale-Revised (CJCS-R). This scale thus consists of 11 items assessing caregivers' cultural reasons for caring for elderly relatives and their views on expectations about caregiving (e.g., "I provide care because it is my duty to care for elderly dependent family members"), with response options ranging from 0 "strongly disagree" to 4 "strongly agree". Dilworth-Anderson *et al.* (2004) found a unidimensional structure of the Cultural Justifications for Caregiving Scale, showing that higher scores indicated having strong cultural reasons for providing care, as evidenced by caregivers' identification with norms, beliefs, and expectations. In the present study, the internal consistency (Cronbach's alpha) for the scale was 0.89.

b) Stressors

Frequency of behavioural problems. This variable was assessed with the Revised Memory and Behaviour Problems Checklist (Teri *et al.*, 1992), which consists of a 24-item scale that measures the frequency of observable behavioural problems (e.g., "During the past week, how often did your relative forget which day of the week it was?"). Scores range from 0 = "not at all" to 4 = "extremely". In this study the internal consistency was 0.81 (Cronbach's alpha).

c) Resources

Rumination. Rumination was assessed using the short version of The Ruminative Responses Scale (RRS-reduced version; Jackson & Nolen-Hoeksema, 1998), which is a 10-item measure assessing self- and symptom-focused responses to sadness and distress

(e.g., "I think about how sad I feel"). Scores range from 0 "never" to 3 "always". Internal consistency in this study was 0.86 (Cronbach's alpha).

Cognitive reappraisal. Cognitive reappraisal was assessed using four items selected from the Mood Repair subscale from the Trait Meta-Mood Scale (TMMS-24; Salovey, Mayer, Goldman, Turvey & Palfai, 1995). Items (e.g., "No matter how badly I feel, I try to think about pleasant things") rate respondents' ability to cognitively construct a potentially negative emotion-eliciting situation in a way that changes its emotional impact. Response options range from 0 "never" to 3 "always". In this study, internal consistency (Cronbach's alpha) was 0.85.

d) Outcome variables

Depression. The Center for Epidemiological Studies-Depression Scale (CES-D; Radloff, 1977) was used, an instrument consisting of 20 items that assess the frequency of depressive symptomatology during the previous week (i.e., "I felt that everything I did was an effort"), with scores ranging from 0 "rarely or none of the time" to 3 "most or all of the time". In this study, the internal consistency (Cronbach's alpha) was 0.89.

Anxiety. Anxiety was measured with the Tension-Anxiety subscale from the Profile of Mood States (POMS; McNair, Loor & Droppleman, 1971). This instrument consists of 9 items assessing anxiety level during the previous week (i.e., "anxious"). Scores range from 0 "not at all" to 4 "very much". In this study, the scale presents an internal consistency of 0.91 (Cronbach's alpha).

Anger. Anger was assessed using the State Anger subscale from the State-Trait Anger Expression Inventory (Spielberger, 1988). This is a 10-item measure that assesses self-reported level of anger (e.g., "I fly off the handle"), with response options ranging

from 0 “not at all” to 3 “a lot”. Internal consistency (Cronbach’s alpha) of this scale in the present study was 0.88.

6.4 Data Analysis

Normality and the presence of univariate and multivariate outliers were tested following the Tabachnick and Fidell (1996) criteria. An exploratory factor analysis of the CJCS-R scale using principal components analysis (with varimax rotation) was carried out, using Kaiser’s rule of retaining factors with eigenvalues greater than 1 ($\lambda \geq 1$). Subsequent analyses (ANOVAs and effect sizes), using the results of the factor analysis, were carried out and are described in the results section.

6.5 Results

6.5.1 Outliers, multicollinearity and normality

Skewness and kurtosis were within the expected values. Neither univariate nor multivariate outliers (Mahalanobis distance at $p < 0.001$) were found.

6.5.2 Dimensional analysis of the Cultural Justifications for Caregiving Scale-Revised

Principal components factor analysis of the 11 items was carried out using varimax rotation. Two factors were obtained with eigenvalues higher than 1, which explained 61.61% of the total variance. Information on item loadings (in all cases item loadings for each factor were higher than 0.40) is shown in Table 6.2. The first factor was labelled “Intrinsic motives for caregiving”, as it includes 7 items related to internalized and entrenched reasons for providing care that are less influenced by social and obligation-based norms and expectations (e.g., “I feel as though I am being useful and making a

family contribution"). The first factor explained 40.73% of the variance. This factor seems to be linked with motives for caregiving that are connected with caregivers' personal values. The second factor was labelled "Extrinsic motives for caregiving". It consists of 4 items that measure reasons to care linked to obligation, sense of responsibility and social pressure (e.g., "I have no choice"). The second factor explained 20.88% of the variance. Extrinsic motives for caregiving are more related with imposed values or external reasons which guide caregivers´ behavior even though they may not be in line with caregivers´ own personal values.

Table 6. 2. Factor analysis of the CJCS-R items.

	Factors	
Items **I provide care because:**	**Factor 1**	**Factor 2**
- I was taught by my parents to take care of elderly dependent family members.	**0.682**	
- of my religious and spiritual beliefs.	**0.614**	
- by giving care to elderly dependent family members, I am giving back what has been given to me.	**0.794**	
- it strengthens the bonds between me and them.	**0.785**	
- I was raised to believe that care should be provided in the family.	**0.828**	
- it is what my people have always done.	**0.830**	
- I feel as though I am being useful and making a family contribution.	**0.703**	
- it is my duty to provide care to elderly dependent family members.		**0.582**

	Factors	
- it is important to set an example for the children in the family.		**0.601**
- my family expect me to provide care.		**0.677**
- I have no alternative.		**0.861**
Eigenvalue	5.48	1.29
% Variance	40.73	20.88

Note. Numbers in bold in each column represent items clustered to the corresponding factor. Items < 0. 40 are not shown.

6.5.3 Reliability

The CJCS-R had an internal consistency of 0.89 (Cronbach's alpha) for the total scale, 0.90 for the Intrinsic motives for caregiving factor and 0.73 for the Extrinsic motives for caregiving factor.

6.5.4 Descriptive data and correlation analysis

Descriptive information about the assessed variables (means, standard deviations and ranges) is shown in Table 6.3. Correlational analysis (see Table 6.3) between the obtained motives for caregiving factors and the assessed variables showed that intrinsic motives for caregiving correlated positively and significantly with cognitive reappraisal. Also, higher scores on intrinsic motives were significantly associated with lower scores on rumination. Finally, extrinsic motives were significantly and positively associated with caregiver anxiety.

Table 6. 3. Correlations, Means, Standard Deviations and Ranges of the assessed variables.

	1	2	3	4	5	6	7	Mean	SD	Range
1. Intrinsic motives								13.61	6.03	0-21
2. Extrinsic motives	0.58**							7.18	3.48	0-12
3. Frequency of behavioural problems	-0.03	0.07						35.40	13.32	2-77
4. Rumination	-0.16*	0.05	0.19*					9.44	6.06	0-26
5. Cognitive reappraisal	0.20**	0.11	-0.00	-0.40**				6.35	3.41	0-12
6. Anger	-0.02	0.10	0.15*	0.36**	-0.24**			7.25	5.39	0-21
7. Depression	-0.07	0.11	0.24**	0.63**	-0.43**	0.29**		17.98	11.61	0-55
8. Anxiety	-0.01	0.15*	0.25**	0.58**	-0.33**	0.40**	0.70**	16.61	9.25	0-36

(* $p < 0.05$; ** $p < 0.01$)

6.5.5 Differences between groups in the assessed variables by motives for caregiving

Participants were coded as high or low in extrinsic and intrinsic motives, respectively, based on median splits for each factor. Four groups, corresponding to four different motivation profiles, were created: HIHE = High in Intrinsic Motives and High in Extrinsic motives (n = 61); LILE = Low in Intrinsic Motives and Low in Extrinsic Motives (n = 61); HILE = High in Intrinsic Motives and Low in Extrinsic Motives (n = 23); and LIHE = Low in Intrinsic Motives and High in Extrinsic Motives (n = 21).

With a view to analyzing differences between types of motives for caregiving, ANOVAs were carried out to permit the analysis of differences between these groups in the following variables: 1) *stressors* (hours caring per day, time since caring began and frequency of behavioural problems) 2) *caregivers' resources* (rumination and cognitive reappraisal), and 3) *outcome variables* (depression, anxiety and anger). In order to test the

effect size of between-group differences in the assessed variables, partial eta-squared (ηp^2) was used with the usual interpretation (small ~ 0.01, medium ~ 0.06 and large ~ 0.14).

With regard to resource variables, univariate ANOVA analyses revealed main group effects for rumination and cognitive reappraisal (Table 6.4). The effect sizes (see Table 6.4) were small for cognitive reappraisal and medium for rumination. In addition, main effects of group were found for the assessed outcome variables (anger, depression and anxiety), with a small effect size for anger and medium for both depression and anxiety. Specifically, the LIHE caregiver group showed significantly higher levels of rumination, anger, depression and anxiety than the other three groups (HIHE/LILE/HILE). The HILE group scored significantly higher in cognitive reappraisal than the HIHE and LIHE groups.

Table 6. 4. Differences between groups in the assessed variables

	Group 1 (LILE) N = 61 Mean ± SD	**Group 2 (HIHE) N = 61 Mean ± SD**	**Group 3 (HILE) N = 23 Mean ± SD**	**Group 4 (LIHE) N = 21 Mean ± SD**	**F**	**p**	**Post-hoc differences**	**ηp^2**
Hours caring per day	10.64±7.62	11.26±7.78	10.33±6.35	12.24±8.76	0.30	0.83	Non-significant differences	0.01
Time since caring began (months)	61.91±56.16	46.10±38.47	54.81±34.28	56.27±49.20	1.15	0.33	Non-significant differences	0.02
Frequency of behavioural problems	34.91±12.30	34.28±13.31	37.06±15.31	39.00±14.38	0.79	0.50	Non-significant differences	0.02
Rumination	9.75±6.03	8.36±5.50	7.95±6.73	13.38±5.61	4.32	< 0.01	Group 4 > than Groups 1, 2 and 3	0.08
Cognitive reappraisal	5.66±3.10	6.87±3.39	7.60±3.57	5.43±3.68	2.83	< 0.05	Group 3 > than Groups 1 and 4	0.05
Anger	6.43±4.49	7.18±5.60	6.75±4.62	10.13±7.09	2.59	< 0.05	Group 4 > than Groups 1, 2 and 3	0.05
Depression	17.33±10.65	16.50±11.13	17.38±12.31	25.10±13.34	3.16	< 0.05	Group 4 > than Groups 1, 2 and 3	0.06
Anxiety	15.28±7.91	16.15±10.07	16.09±9.00	22.38±9.07	3.36	< 0.05	Group 4 > than Groups 1, 2 and 3	0.06

Note. LILE = Low Intrinsic Motives + Low Extrinsic Motives; HIHE = High Intrinsic Motives + High Extrinsic motives; HILE = High Intrinsic Motives + Low Extrinsic Motives; and LIHE = Low Intrinsic Motives + High Extrinsic Motives.

6.6 Discussion

The objectives of this study were to analyze both the structural dimension of the Cultural Justifications for Caregiving Scale-Revised (CJCS-R) and its influence on the different dimensions of the caregiver stress and coping process (stressors, caregiver resources and outcome variables). Inconsistent with our expectations, which were based on previous research suggesting a unidimensional structure of the CJCS (Dilworth-Anderson *et al.*, 2005), the results obtained support a bidimensional structure of the revised scale. Factors were labelled, respectively, intrinsic and extrinsic motives for caregiving, and explained a significant proportion of variance of scores in motives for caregiving. The intrinsic motives for caregiving factor includes reasons to care that are related to sources of caregivers' internal control, such as emotional bonding, religious beliefs and sense of usefulness (personal values), which reflect some degree of personal choice for providing care on the part of caregivers. Extrinsic motives for caregiving are more related to a sense of obligation and social norms and expectations, which leave less room for caregivers' personal choice. Acceptable-to-good internal consistency indexes were found for both subscales and for the total scale. These results may be seen as endorsing the recommendations of Quinn *et al.* (2010), who suggested that, rather than exploring specific reasons for caring, it is more appropriate and useful to categorize the different types of motives under dimensions such egotistic, altruistic, intrinsic or extrinsic (Quinn *et al.*, 2010).

Different patterns of associations were found between the identified factors of motives for caregiving and resource-related and outcome variables assessed in the study. Higher scores on intrinsic motives for caregiving were associated with higher scores on cognitive reappraisal, a coping variable which has been found to have positive effects on distress (Gross & John, 2003). This finding is similar to that reported by Farran, Keane-

Hagerty, Salloway, Kupferer and Wilken (1991), who found that caregivers who were less likely to report making personal choices about life and caregiving showed higher levels of burden and more feelings of powerlessness.

Intrinsic motives for caregiving were also associated with lower scores on rumination, an emotional regulation variable that has been shown to act in a maladaptive way in the stress process (Thomsen, Jorgensen, Mehlsen & Zachariae, 2004). Consistent with the findings of Knight and Sayegh (2010), the results of this study suggest that cultural values, such as intrinsic motives for caregiving, have significant influence on the stress process through their influence on the coping strategies caregivers use to deal with caregiving stressors.

As regards extrinsic motives, a significant and direct association between this dimension and anxiety was found, which is in line with the findings of studies reporting associations between "obligation-based" motives for caregiving and caregivers' burden and stress (Cicirelli, 1993; Lyonette & Yadley, 2003).

However, even though different patterns of association have been found for each motives factor, caregiving motives are not mutually incompatible, as some caregivers may report high scores on obligation motives for caring and, simultaneously, high scores on personal motives for caregiving (Walker *et al.*, 1990). In fact, the importance of considering the specific caregiver motivation profile (combination of intrinsic and extrinsic motives) is clearly supported by the present study, in particular by the results of the analysis of differences between the motivation profiles of caregivers: those who simultaneously scored low on intrinsic motives and high on extrinsic motives (LIHE) were found to have poorer resources for coping with caregiving demands and to report higher levels of caregiver distress, when compared to the other groups. Specifically, the results suggested that those caregivers who cared for extrinsic motives and presented few

intrinsic motives for this role (LIHE) regulated their emotions in a less adaptive way, as they more often used the rumination strategy and less often cognitive reappraisal. These negative influences on their coping resources may help to explain why caregivers from the LIHE group also score higher on distress measures than the other groups. Given that there were no differences between groups in the level of objective stressors, the importance of subjective factors can be deduced from these results.

Hence, the results of this study are in support of findings from previous research stressing the utility of considering the construct of caregiving motives in a multidimensional way, assuming that it is made up of reasons representing different degrees of personal choice vs. obligation. Simultaneously considering the two types of motive (intrinsic and extrinsic) may be of greater interest than analyzing their individual effects, given that it may help both researchers and clinicians identify a profile of caregivers at risk for negative outcomes. According to the present study, this at-risk caregiver profile could be represented by caregivers with low intrinsic and high extrinsic motivation. Thus, detecting caregiving motivation profiles may be of particular relevance to the development, implementation and optimization of interventions with caregivers. In this regard, non-caregiving clinical research is currently highlighting the importance of taking into account people's goals, personal objectives and values in explanations of their behaviour (Hayes, Strosahl & Wilson, 1999). Therapeutic paradigms such as those of Acceptance and Commitment Therapy (ACT; Hayes *et al*., 1999) may be of especial interest for this purpose (Márquez-González, Romero-Moreno & Losada, in press). This approach is based on the notion that fostering people's acceptance of negative internal events (emotions, thoughts and sensations) so that they act more consistently with personal values – which promote intrinsic motives – should be the main objective of therapeutic interventions in cases where a pattern of experiential avoidance is identified.

This perspective may be of particular interest for dementia caregivers, given that dementia is a degenerative disease involving high levels of suffering, much of which is unavoidable. According to Cooper, Katona, Orrel and Livingston (2008), while some types of intervention, such as cognitive-behavioural therapy, have shown themselves to be useful for reducing caregiver distress by training caregivers to deal with specific stressors, there may be some caregiver situations that are less likely to be changed, making such change-oriented interventions potentially ineffective, and even frustrating. In those situations, it may be more useful to train caregivers in strategies which help them to accept and adapt to their situations (or to give up fighting against them) and keep on living the lives they want to live, that is, with commitment to their goals, values and objectives (for example, increasing intrinsic motives for caring).

The present study has some limitations that should be taken into account. First, caregivers were contacted through different social centres, so that the results may not be generalizable to the entire caregiving population (e.g., to those caregivers who are less likely to ask for formal help). Also, results regarding differences between caregiver motivation profile groups should be interpreted cautiously, given that the sample sizes of the LIHE or the HILE may also affect the generalizability of the findings. In addition, causal inferences cannot be drawn, given the cross-sectional nature of the data. In this regard, Hsu and Shyu (2003), analyzing caregiver motivations by rating open questions (e.g., about the decision to care and the manner of doing it), suggested that motives for care may change over the course of the caregiving process; they showed how, at the beginning of care, motives were mainly obligation-based, but that these became progressively substituted by intrinsic motives (e.g., sense of responsibility). It would be interesting in future research to analyze how changes in motives for caregiving may lead to changes in caregiver resources and distress over time. For example, changes from

extrinsic to intrinsic motives over the course of the caring process may lead to a reduction in caregiver distress. Given the possibility of motives for caring undergoing changes during the caregiving process (Hsu & Shyu, 2003), caregivers with low intrinsic motives and high extrinsic motives to care may benefit more from interventions aimed at identifying or increasing additional sources of intrinsic value. Another limitation of the present study is related to the fact that the scale used for measuring motives for caregiving is not exhaustive, and there may be other motives that could be considered relevant for explaining caregiver distress (e.g., giving meaning to life or growth through adversity). In addition, another potential limitation is related with the distinction of the intrinsic and extrinsic dimensions of the CJCS-R scale as it may be difficult to classify certain motives for caring in one or another category (e.g. "I provide care because it is what my people have always done" as an intrinsic motive). In this sense, we consider that it may be helpful to consider this distinction in a flexible way, according to which extrinsic and intrinsic motives may be regarded as the two poles of an extrinsic-intrinsic (or imposed versus chosen) continuum, rather than a dichotomy of mutually exclusive motives. In this continuum, the motive "I provide care because it is what my people have always done" may be situated in a point between more explicit extrinsic motivations such as "I provide care because my family expect me to provide care" and other motivations related with a sense of utility and spiritual meaning which clearly show more degree of personal choice. Furthermore, and as pointed by other authors exploring the influence of motives for caring, it would be interesting to analyze differences between the identified motivation profiles as a function of variables such as gender, kinship or quality of relationship (Dilworth-Anderson *et al.*, 2005; Walker *et al.*, 1990). Finally, considering that cultural differences in motivations for providing care have been found (for example, Greek caregivers are more motivated by the desire to maintain family harmony while American

caregivers reported financial reasons more frequently; Kabitsi & Powers, 2002), the obtained results may not be generalizable to caregivers from other cultures different from the one analyzed in this study.

Examination of the motives for caregiving may have implications not only for caregiver outcomes but also for the care recipients, as suggested by Feeney and Collin (2003). These authors found that different motivations for caregiving predicted quality of care through different patterns of caregiving behaviour and even the continuation of care: those caregivers who provided care mainly as an obligation were less responsive and more overinvolved than those who cared on the basis of altruistic reasons.

In conclusion, the results of this study support the importance of analyzing motives for caregiving, given the potential contribution to the explanation of differences in caregivers' resources and distress. In particular, this study suggests that intrinsic and extrinsic motives for caregiving are not mutually exclusive, and may combine with one another to provide a better explanation of the impact caregiving has on caregivers' well-being and adaptation. The consideration of motives for caregiving as a bidimensional construct appears to be especially useful for identifying caregivers at risk.

6.7 References

Campbell, D.L., & Martin-Mathews, A. (2003). The gendered nature of men's filial care. *The Journals of Gerontology, 58*, 350-358.

Carruth, A.K. (1996). Motivating factors, exchange patterns, and reciprocity among caregivers of parent with and without dementia. *Research in Nursing and Health, 19,* 409-419.

Cicirelli, V.G. (1993). Attachment and Obligation as Daughters' Motives for Caregiving Behavior and Subsequent Effect on Subjective Burden. *Psychology and Aging, 8*, 144-155.

Cooper, C., Katona, C., Orrel, M., & Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry, 23,* 929-936.

Dilworth-Anderson, P., Brummett, H.B., Goodwin, P., Williams, S.W., Williams, R.B., & Siegler, I.C. (2005). Effect of Race on Cultural Justifications for Caregiving. *Journal of Gerontology: Social Sciences, 60*, 257-262.

Dilworth-Anderson, P., Goodwin, P.Y., & Williams, S.W. (2004). Can Culture Help Explain the Physical Health Effects of Caregiving Over Time Among African American Caregivers? *Journal of Gerontology: Social Sciences, 59*, 138-145.

Dilworth-Anderson, P., Williams, S.W., & Cooper, T. (1999). Family caregiving to elderly African Americans: caregiver types and structures. *Journals of Gerontology: Psychological Sciences and Social Sciences, 54*, 237-241.

Dilworth-Anderson, P., Williams I.C., & Gibson, B.E. (2002). Issues of race, ethnicity, and culture in caregiving research: a 20-year review (1980-2000). *The Gerontologist, 42,* 237-272.

Farran, C.J., Keane-Hagerty, E., Salloway, S., Kupferer, S., & Wilken, C.S. (1991). Finding meaning: an alternative paradigm for Alzheimer's disease family caregivers. *The Gerontologist, 31,* 483-489.

Feeney, B.C., & Collins, N.L. (2003). Motivations for caregiving in adult intimate relationships: influences on caregiving behavior and relationship functioning. *Personality and Social Psychology Bulletin, 29*, 950-968.

Gross, J.J., & John, O.P. (2003). Individual Differences in Two Emotion Regulation Processes: Implications for Affect, Relationships, and Well-Being. *Journal of Personality and Social Psychology, 85,* 348-362.

Haley, W.E., Levine, E.G., Brown, L., & Bartolucci, A.A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging, 2,* 323-330.

Hayes, S.C., Strosahl, K., & Wilson, K.G. (1999). *Acceptance and Commitment Therapy: An experiential approach to behavior change*. New York: Guilford Press.

Hsu, H., & Shyu,Y.L. (2003). Implicit exchanges for family caregiving for frail elders in Taiwan. *Qualitative Health Research, 13,* 1078-1093.

IMSERSO (2005). *Cuidados a las personas mayores en los hogares españoles. El entorno familiar* [Caring for older persons in Spanish homes. The family environment]. Madrid: IMSERSO.

Jackson, B., & Nolen-Hoeksema, S. (1998). *The Emotion-Focused Coping Questionnaire.* Manuscript in progress.

Kabitsi, N., & Powers, D.V. (2002). Spousal motivations of care for demented older adults: a cross-cultural comparison of Greek and American female caregivers. *Journal of Aging Studies, 16,* 383-399.

Knight, B.G., & Sayegh, P. (2010). Cultural values and caregiving: the updated Sociocultural Stress and Coping Model. *Journal of Gerontology: Psychological Sciences, 65,* 5-13.

Knight, B.G., Silverstein, N., McCallum, T.J., & Fox, L.S. (2000). A sociocultural stress and coping model for mental health outcomes among African American caregivers in Southern California. *Journal of Gerontology: Psychological Sciences and Social Sciencies, 55*(3), 142-150.

Losada, A., Márquez-González, M., Knight, B., Yanguas, J., Sayegh, P., & Romero-Moreno, R. (2010). Psychosocial factors and caregivers´ distress: Effects of familism and dysfunctional thoughts. *Aging and Mental Health, 14,* 193-202.

Lyonette, C., & Yardley, L. (2003). The influence on carer wellbeing of motivations to care for older people and the relationship with the care recipient. *Aging and Society, 23*, 487-506.

Márquez-González, M., Romero-Moreno, R., & Losada, A. (in press). Caregiving issues in a therapeutic context: new insights from the Acceptance and Commitment approach. In K. Laidlaw and N. Pachana, (Eds.). *Casebook of Clinical Geropsychology: International Perspectives on Practice*. New York: Oxford University Press.

McNair, D., Lorr, M., & Droppleman, L. (1971). *Profile of Mood States. Manual*. San Diego: Educational and Industrial Testing Service.

Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging 18,* 250-267.

Pinquart, M., & Sörensen, S. (2005). Ethnic differences in stressors, resources and psychological outcomes of family caregiving: a meta-analysis. *The Gerontologist, 45,* 90-106.

Quinn, C., Clare, L., & Woods, R.T. (2010). The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: a systematic review. *International Psychogeriatrics, 22*, 43-55.

Radloff, L.S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1,* 385-401.

Salovey, P., Mayer, J.D., Goldman, S.L., Turvey, C., & Palfai, T.P. (1995). Emotional attention, clarity, and repair: Exploring emotional intelligence using the Trait Meta-Mood Scale. In J.W. Pennebaker, (Eds). *Emotion, Disclosure, and Health* (pp.125-154). Washington, D.C.: American Psychological Assn.

Spielberger, C.D. (1988). *State-trait anger expression inventory. Research edition*. Odessa, FL: Psychological Assessment Resources.

Tabachnick, B.G., & Fidell, L.S. (1996). *Using multivariate statistics* (3rd ed.). New York: Harper Collins.

Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P.P. (1992). Assessment of Behavioral Problems in Dementia: The Revised Memory and Behavior Problems Checklist. *Psychology and Aging, 7,* 622-631.

Thomsen, D.K., Jorgensen, M.M., Mehlsen, M.Y., & Zachariae, R. (2004). The influence of rumination and defensiveness on negative affect in response to experimental stress. *Scandinavian Journal of Psychology, 45,* 253-258.

Vitaliano, P.P., Young, H.M., & Zhang, J. (2004). Is caregiving a risk factor for illness? *Current Directions in Psychological Science,* 13, 13-16.

Walker, A.J., Pratt, C.C., Shin, H., & Jones, L.L. (1990). Motives for parental caregiving and relationship quality. *Family Relations, 39*, 51-56.

3

ESTUDIO TRES

EFFECTS OF THE FREQUENCY AND SATISFACTION WITH LEISURE PROFILE ON DEMENTIA CAREGIVERS DISTRESS

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. *Revista objetivo: Behaviour Resarch & Therapy*

7. Estudio Tres: Effects of the frequency and satisfaction with leisure profile on dementia caregivers distress

7.1 Abstract

Introduction

Dementia caregiving is linked with negative consequences for mental and physical health for caregivers. The number of studies analyzing the influence of leisure on caregivers' distress is sparse. The PEAR (pleasant events-activity restriction) model has been proposed as a way for understanding leisure effects on caregivers' distress.

Objective and method

Taking into account both the PEAR model and the stress and coping model, the potential of both frequency and satisfaction with leisure to help us explain caregivers' distress (depression, anxiety and perceived health), risk of institutionalization of the care recipient, caregivers' stressors (time caring, daily hours caring, functional status and behavioral problems) and modulator variables (rumination and cognitive reappraisal), was analyzed in 275 dementia caregivers.

Results

The sample was divided in four groups based on caregivers' scores on frequency and satisfaction with leisure: LFLS = Low frequency + low satisfaction; LFHS = Low frequency and high satisfaction; HFLS = High frequency + low satisfaction; HFHS = High frequency + high satisfaction. Principal group effects were found for stressors, mediating variables, distress and risk of institutionalization. Compared with the other groups, caregivers from the HFHS group showed a generally more positive profile on mediator's variables, health outcomes and lower levels of risk of institutionalization. In

addition, although there were no differences between groups in functional status, time caring and daily hours devoted to caregiving, caregivers from the LFLS group, compared with the other groups, used significantly less adaptive emotional regulation strategies and showed worse consequences on health outcomes.

Conclusion

The results of this study suggest the importance of considering caregivers' profile on frequency (doing leisure activities) and satisfaction (enjoying them) with leisure in order to understand caregiving distress. Caregivers showing high frequency and high satisfaction with leisure (HFHS) show better outcomes and also report using better emotion regulation strategies. On the contrary, neither doing nor enjoying leisure activities seems to determine a profile of caregivers at risk for negative outcomes. Regarding interventions aimed at fostering behavioral activation, not any type of leisure activity seems to be useful for caregivers, but only those really enjoyed by caregivers.

Keywords: activity restriction, caregivers, dementia, emotion regulation, behavioral activation, leisure, pleasant events, physical and mental health, risk of institutionalization.

7.2 Introduction

It is well known that dementia caregiving is associated with psychological and physical health problems for caregivers (e.g., Pinquart & Sörensen, 2003). Due to the high demands (number of tasks and daily hours caring) required to provide care for a loved one during a long period of time, dementia caregiving has been considered as a chronic stressful situation (Vitaliano, Young & Zhang, 2004). The most commonly theoretical approach used in caregiving literature is the stress and coping model adapted to caregiving, which has received significant empirical support (Haley, Levine, Brown, & Bartolucci, 1987; Knight & Sayegh, 2010). Following this model, the impact that caregiving stressors (e.g., care-recipient frequency of behavioral problems or care-recipient functional capacity) has on caregivers outcomes (e.g., depression or physical health) depends on mediating variables (e.g., coping strategies) that may attenuate or increase the influence of stressors on caregivers' health.

7.2.1 Behavioral activation and caregiver distress

One of the coping variables that has been found to have a positive influence on caregivers' mental and physical health is the level of caregivers' behavioral activation or engagement in pleasant events or leisure. Specifically, it has been found that higher levels of behavioral activation were significantly associated with higher levels of psychological well-being, life satisfaction and positive affect, and lower levels of burden and depression in caregivers (Croezen, Haveman-Nies, Alvarado, Van`T Veer & De Groot, 2009; Hirano, et al., in press; López, López-Arrieta & Crespo, 2005; Losada et al., 2010; Mausbach, Coon, Patterson & Grant, 2008; Mausbach, Roepke, Depp, Patterson & Grant, 2009; Thompson et al., 2002; Warr, Butcher, & Robertson, 2004). These positive effects of leisure have been found even after controlling other relevant variables in the caregiving

stress process, such us socio-demographic variables, care recipients' functional status and caregivers' social support (Losada et al., 2010), and are consistent with Lewinsohn's theory (1975) on the explanation of depression, which suggests that low levels of reinforcement for engagement in pleasant events predict significantly higher levels of depression.

Significant associations between behavioral activation and variables that influence caregiving outcomes have also been found. Caregivers with lower levels of activity participation reported higher levels of negative appraisals and both variables significantly predicted caregivers' depressive symptomatology (Mausbach et al., 2009). Similarly, it has been found that lower levels of behavioral activation were significantly linked with a more frequent use of rumination strategy in a non-caregivers sample (Raes, Hoes, Van Gucht, Kanter, & Hermans, 2010). These results suggested that behavioral activation may have a significant impact not only on caregivers' distress but also on the way caregivers use emotion regulation strategies, which may impact caregivers' mental health outcomes, as significant associations between emotional regulation (e.g. rumination and cognitive reappraisal) and psychopathology (e.g. depression and anxiety) have been found (Aldao, Nolen-Hoeksema & Schweizer, 2010).

7.2.2 Satisfaction with leisure and caregiver distress

Research has shown that not only behavioral activation or frequency of leisure is important. The importance of considering the individual's subjective feelings regarding leisure participation has also been highlighted, given that individual differences in values and preferences influencing on whether leisure is satisfying or not do exist (Stevens et al., 2004). Satisfaction with leisure has been considered as a subjective dimension of behavioral activation (Stevens et al., 2004) and empirical support has been found linking

this variable with caregiver distress. Specifically, it has been found that reporting higher levels of leisure satisfaction was significant and negatively associated with depression and anxiety (Raj, Manigandan & Jacob, 2006), guilt (Losada et al., 2010) and burden (Lund et al., 2009).

A concept related with satisfaction with leisure is activity restriction, or the perception of the extent to which different areas of activity (e.g. self-care, visiting friends, working on hobbies) are restricted by stressful life events (Williamson & Shaffer, 2000; Williamson & Schulz, 1992). Williamson & Shaffer (2000) developed the Activity Restriction Model, which suggested that the extent to which one's normal activities are restricted by significant stressors (such as behavioral problems of care-recipients) plays a central role in reductions of psychosocial adjustment resulting in poorer mental health (e.g. depression). Because activity restriction is related with the cognitive appraisal that one is not able to engage in as much activity as one would like, it may be considered as dissatisfaction with engagement in leisure activities (Mausbach, Cardenas, Goldman & Patterson, 2007) or otherwise, a measure of satisfaction with leisure time (Mausbach, Roepke, Depp, Moore, Patterson & Grant, in press). Mausbach, Patterson & Grant (2008) found that activity restriction had an important role in explaining increased depressive symptoms in Alzheimer caregivers when compared to non-caregivers, suggesting that activity restriction mediates the relationship between caregiver status and caregivers´ depression.

7.2.3 The caregiving "PEAR" (Pleasant Events and Activity Restriction) Model

Most of the studies that have been done analyzing caregiving and leisure have centered their attention on analyzing either the frequency of pleasant events or the satisfaction with them to predict caregiver distress. However, several researchers have

highlighted the importance of considering both dimensions at the same time: frequency and satisfaction (Benyamini, & Lomranz, 2004; Mausbach et al., 2007; Mausbach et al., 2008). Empirical support for this idea has been reported by Mausbach et al. (2008), who found that the number of activities was significantly correlated with positive affect, while the obtained pleasure from activities was associated with both higher scores on positive affect and lower levels of negative affect (Mausbach et al., 2008). Considering these results, Mausbach et al. (in press) developed the Pleasant Events and Activity Restriction Model ("PEAR" model). Through this model, more precise predictions of caregiver health and well-being are done by considering both a measure of frequency of pleasant events and the subjective experience of feeling restricted from engaging in activities (Mausbach et al., in press). When testing their model, Mausbach et al. (in press) conducted a study with 108 spousal dementia caregivers and found that those caregivers with low levels of pleasant events and high activity restriction showed significantly higher scores on caregivers' distress (depressive symptoms, negative affect, and overload) and poorer coping strategies and resources (personal mastery and self-efficacy) compared with those caregivers with high levels of pleasant events and low activity restriction, or with those caregivers with either high pleasant events and high activity restriction or low pleasant events and low activity restriction (Mausbach et al., in press).

Drawing upon the stress and coping model and the "PEAR" model, the aim of this study is to analyze the advantages of considering both frequency of and satisfaction with leisure to explain caregiver distress. We analyzed caregivers with low frequency of pleasant events and low levels of satisfaction with them (LFLS) and those with both high frequency of and high satisfaction with them (HFHS). However, our study adds to the Mausbach et al. (in press) study the consideration of two additional groups of caregivers based on their scores on frequency and satisfaction with leisure: caregivers who engage in

high frequency of pleasant events and report low levels of satisfaction with them (HFLS), and those who engage in low frequency of pleasant events and report high levels of satisfaction with them (LFHS).

These groups will be compared on their scores in variables taping the different dimensions included in the stress and coping model: stressors (time caring, daily hours caring, functional status and behavioral problems), mediating variables (rumination and cognitive reappraisal), and health outcomes (depression, anxiety and perceived health). In addition, the effect that the caregiver leisure profile has on risk of institutionalization of the care-recipient will be also assessed, following suggestions by previous research (Mausbach et al., in press).

Drawing upon Mausbach et al. (in press) previous results, we hypothesize that caregivers with low frequency of pleasant events and low satisfaction with them (LFLS) will show lower levels of health outcomes and less adaptive emotional regulation strategies (higher use of rumination and lower use of reappraisal) than the other three groups. In addition, we expect the group formed by those caregivers with high frequency of pleasant events and high satisfaction with them (HFHS) to be the one reporting more adaptive results. Specifically, we hypothesize that this profile of caregivers (HFHS) will report lower levels of stressors, more frequent use of adaptive emotional regulation strategies and better health outcomes. Finally, we hypothesize significant and negative associations between frequency and satisfaction with leisure and risk of institutionalization.

7.3 Method

7.3.1 Participants and procedure

The sample consisted of 275 caregivers of relatives with dementia living in the community. They were recruited through Social Services and Day Care centers from Madrid (Spain) or by announcements on the media (i.e., radio or television). In order to participate in the study, caregivers had to identify themselves as the main source of help for their love ones, being older than 18 years old and providing care (caregiving tasks) at least one hour per day during a period of 3 consecutive months. In order to test if caregivers met the inclusion criteria, initial telephone interviews were conducted. Then, face-to-face interviews were carried out in the different Social and Day Care centers. All caregivers provided their consent to collaborate in the study and the research was approved by both the Spanish Ministry of Education and the Ethics Committee at the Universidad Rey Juan Carlos (Madrid).

7.3.2 Variables and instruments

The selection of the variables has been done drawing upon the dimensions composing the stress and coping model (Haley et al., 1987). In addition to the sociodemographic variables, the following variables were assessed:

a) Frequency of leisure activities

Frequency of pleasant events was assessed using an adaptation of the Leisure Time Satisfaction measure (Stevens *et al.*, 2004). This 6-item scale measures caregivers´ frequency of engagement in 6 different pleasant events over the past month (e.g., "How often have you participated in hobbies or other interests"*),* with scores ranging from 0 "not

at all" to 4 "a lot". Internal consistency (Cronbach's alpha) of the scale was.72 in this study.

b) Satisfaction with leisure

Satisfaction with pleasant events was measured using the Leisure Time Satisfaction (LTS) scale (Stevens *et al.*, 2004) which consists of 6 items assessessing the level of caregivers' leisure time satisfaction regarding different activities over the past month (e.g., "How satisfied are you with the amount of time you have been able to spend taking part in hobbies or other interests?"). Answers ranged from 0, "not at all" to 2 "a lot". The internal consistency (Cronbach´s alpha) in this study was .86.

c) Stressors

Time since caregiving began (months caring) and daily hours caring were considered as stressors.

Patient Behavioral Problems. Frequency of behavioral problems in dementia patients was measured using the Revised Memory and Behaviors Problems Checklist (Teri *et al.*, 1992). It consists of a 24 item-scale (e.g., "During the past week; how often did your relative start but not finish things?) with scores ranging from from 0 = "not at all" to 4 = "extremely". The internal consistency (Cronbach's alpha) found for this study was .82.

Functional status. Patients' functional status was assessed with the Barthel Index (Mahoney and Barthel, 1965), a 10-item scale that measures the level of independence for Activities of Daily Living (ADL) (e.g., "What extent is your relative able to bathing by her/his self?). Scores range from 0 = "dependent" to 100 = "independent", with higher

scores suggesting higher level of independence of the care-recipient. In this study, the internal consistency (Cronbach's alpha) that has been found was .92.

d) Resources variables

Rumination. The reduced version of The Ruminative Responses Scale (RRS-reduced version; Jackson and Nolen-Hoeksema, 1998) was used. This scale is a 10 item-measure that evaluates the reactions to distress that are self-focused and symptom-focused (e.g., Go away by yourself and think about why you feel this way"). Item scores range from 0 "never" to 3 "always". In this study, internal consistency (Cronbach´s alpha) was .88.

Cognitive reappraisal. It was measured using the Mood Repair subscale from the Trait Meta-Mood Scale (TMMS-24; Salovey, Mayer, Goldman, Turvey & Palfai, 1995). This subscale has 4 items (e.g., "Although I am sometimes sad, I have mostly optimistic outlook"), which assess the ability to repair unpleasant moods or maintain pleasant ones. Item scores range from 0 "never" to 3 "always" and the internal consistency (Cronbach´s alpha) that has been found for this study was .86.

e) Outcome variables

Depression. It was measured using the Center for Epidemiological Studies-Depression Scale (CES-D; Radloff, 1977). It consists of 20 items that measure the frequency of depressive symptomatology during the last week (e.g., "I was bothered by things that usually don't bother me"). Item scores range from 0 "rarely or none of the time" to 3 "most or all of the time". Internal consistency (Cronbach's alpha) of this scale in this study was .89.

Anxiety. It was assessed using the Tension-Anxiety subscale of the Profile of Mood States (POMS; McNair, Lorr & Droppleman, 1971). This scale consists of 9 items evaluating the level of anxiety during last week (e.g., "Anxious"). Answers range from 0 "not at all" to 4 "very much". In this study, internal consistency of the scale was .90 (Cronbach's alpha).

Perceived health. The caregivers´ perception of the overall health was measured using the one single-item "In this moment, how do you consider your health?" Answers ranged on a Likert scale from 0 ("very bad") to 4 ("very good").

f) Risk of institutionalization

Risk of institutionalization was measured using a single item which consisted of asking caregivers "During the past week; how often did you think about the possibility of institutionalize your relative into a residence?". Scores ranged from 0 ("I haven't thought about it at all") to 100 ("I think about it every day").

7.4 Data analysis

Following Tabachnick and Fidell (1996) criteria, normality and the presence of outliers (univariate and multivariate) were tested.

The sample was divided in four groups based on caregivers' scores on frequency and satisfaction with pleasant events. Caregivers were coded as high or low in frequency and satisfaction with pleasant events, respectively, based on their median splits in each variable. The four groups were: 1) Low frequency + low satisfaction (LFLS); 2) Low frequency and high satisfaction (LFHS); 3) High frequency + low satisfaction (HFLS); and 4) High frequency + high satisfaction (HFHS).

In order to test significant differences between these groups in different domains (stressors, emotional regulation strategies and outcome variables), a MANOVA was conducted, using Wilks' criterion. Specifically, stressors domain consisted of scores on time caring (in months), daily hours caring, frequency of behavioural problems and care recipient' functional capacity; emotional regulation strategies domain was composed of rumination and cognitive reappraisal scores; and the outcomes domain included caregiver' depression, anxiety and perceived health scores. In order to control for familywise error, the critical value for alpha for stressors was adjusted to 0.125 (.05/4). For emotional regulation strategies and outcome variables, alphas were adjusted to .025 and. 017, respectively.

In addition, in order to compare the sociodemographic characteristics by group, ANOVA and chi-square analysis were conducted for linear and categorical variables, respectively.

7.5 Results

7.5.1 Outliers, normality, homogeneity of variance and descriptive data

Two univariate outliers (z score higher of 3.29; $p < .001$) were found for both frequency of pleasant events and satisfaction with them and were deleted. One multivariate outlier (Mahalanobis distance at $p < .001$) was found and was deleted. Skewness and kurtosis were within the expected values. Levene's tests were used to analyze homogeneity of group variances and significant effects were found for frequency of pleasant events, satisfaction with pleasant events, depression and risk of institutionalization. The Brown-Forsythe and Welch statistics were used to control non-homogeneity of group variances for these variables and significant group effects were found for all these variables.

The sociodemographic characteristics of the final sample (N = 272) are shown in Table 7.1.

Table 7. 1. Differences between groups in caregiver and care-recipient characteristics.

	Total sample (N=275)	**LFLS (N=92)**	**LFHS (N=29)**	**HFLS (N=51)**	**HFHS (N=103)**	**F, χ^2**	**p-value**
Female, n (%)	218(79.27)	76 (82.61)	25(86.21)	45(88.24)	72(69.90)	10.10	<.05
Caregiver age M (SD)	60.22(12.07)	58.39(11.71)	59.83(13.85)	57.94(10.81)	63.13(12.02)	3.57	<.05
Relationship with care-recipient, n (%)						10.30	.59
Spouses	101(36.73)	30(32.61)	12(41.38)	14(27.45)	45(43.69)		
Daughters/Sons	160(58.18)	55(59.78)	17(58.62)	34(66.67)	54(52.43)		
Others	14(5.1)	7(7.60)	0(0.00)	3(5.88)	4(3.88)		
Care-recipient disease n (%)						12.83	.38
Alzheimer Disease	158(57.45)	48(52.17)	13(44.83)	33(64.70)	64(62.14)	5.28	.15
Other dementia	117(42.55)	44(47.83)	16(55.17)	18(35.30)	39(37.86)		
Frequency of pleasant events	7.84(4.35)	3.84(1.81)	4.34(1.62)	9.28(2.16)	11.68(3.34)	179.15	<.001
Satisfaction with pleasant events	6.56(3.59)	3.10(1.99)	8.59(1.57)	4.76(1.41)	9.97(2.02)	246.99	<.001

Note. LFLS = Low frequency of pleasant events + low satisfaction with pleasant events; LFHS = Low frequency of pleasant events and high satisfaction with pleasant events; HFLS = High frequency of pleasant events + low satisfaction with pleasant events; HFHS = High frequency of pleasant events + high satisfaction with pleasant events.

7.5.2 Correlation analyses

Correlation analyses (see Table 7.2) between both frequency and satisfaction with leisure and the assessed variables showed that, while frequency of leisure was significantly and positively correlated with the care recipients´ functional capacity, satisfaction with leisure had a significant and negative relationship with frequency of behavioral problems. In addition, those caregivers with high levels of both frequency and satisfaction with leisure showed lower scores on rumination, higher levels of cognitive reappraisal and higher scores on depression, anxiety and higher levels of perceived health.

Finally, both frequency and satisfaction with leisure were significantly and negatively correlated with risk of institutionalization.

Table 7. 2. Bivariate correlations between frequency and satisfaction with leisure and the other assessed variables.

	Frequency of pleasant events	**Satisfaction with pleasant events**
Frequency of behavioral problems	-.12	-.23**
Functional capacity	.15**	.11
Rumination	-.38**	-.44**
Cognitive reappraisal	.27**	.31**
Depression	-.41**	-.48**
Anxiety	-.36**	-.42**
Perceived health	.24**	.24**
Risk of institutionalization	- .15*	-.22**

($p < 0.05$; ** $p < 0.01$)

7.5.3 Differences between groups in the assessed variables

Mean and standard deviations of the assessed variables for the whole sample and by frequency and satisfaction with leisure group profile are shown in Table 7.3. In addition, in order to analyze the effect size of between-group differences in the assessed variables, partial eta-squared (ηp^2) was analyzed (small ~ .01, medium ~ .06, and large ~ .14).

Results of MANOVA analyses testing group differences in different domains (stressors, mediating variables and outcome variables) and ANOVA analyses for the individual dependent variables are described below.

Table 7. 3. Differences between groups in the assessed variables.

	Total sample (N=272)	LFLS (N=92)	LFHS (N=29)	HFLS (N=50)	HFHS (N=101)	F	p-value
Time caring, M (SD)	54.80(46.03)	57.80(52.93)	49.97(38.62)	60.80(51.28)	50.49(37.97)	.83	.48
Daily hours caring, M (SD)	10.75(7.56)	11.51(7.68)	10.19(7.85)	8.38(6.43)	11.39(7.73)	2.28	.08
Behavioral problems M (SD)	35.17(14.68)	38.53(14.58)	30.48(14.45)	36.96(13.30)	32.56(14.85)	4.03	<.001
Functional capacity	67.21(30.21)	64.64(31.78)	66.76(27.47)	63.82(31.29)	71.35(28.88)	1.07	.36
Rumination M (SD)	9.25(6.42)	12.38(6.34)	9.00(6.16)	10.50(6.23)	5.84(4.88)	21.38	<.001
Cognitive reappraisal M (SD)	6.51(3.42)	5.28(3.10)	6.76(3.57)	6.24(3.19)	7.69(3.41)	8.81	<.001
Depression M (SD)	17.85(11.70)	24.38(12.31)	15.79(10.01)	18.33(10.48)	12.26(8.91)	21.53	<.001
Anxiety M (SD)	16.17(8.84)	19.97(8.92)	15.24(7.19)	17.36(8.50)	12.38(7.81)	14.01	<.001
Perceived physical health M (SD)	2.20(1.08)	1.87(1.03)	2.48(1.02)	2.26(1.19)	2.40(1.02)	4.90	<.001
Risk of institutionalization M (SD)	16.18(29.85)	21.43(33.95)	15.86(31.91)	20.90(33.59)	9.21(21.10)	3.27	<.05

Note. LFLS = Low frequency of pleasant events + low satisfaction with pleasant events; LFHS = Low frequency of pleasant events and high satisfaction with pleasant events; HFLS = High frequency of pleasant events + low satisfaction with pleasant events; HFHS = High frequency of pleasant events + high satisfaction with pleasant events.

a) Sociodemographic characteristics

As it is shown in Table 7.1, significant group effects were found for age. Specifically, HFHS caregivers were significantly older than LFLS ($p < .001$) and HFLS ($p < .001$). In addition, those caregivers from the HFHS group were significantly more likely to be male and those from the HFLS group were significantly more likely to be female compared to the other groups. In addition, as expected, significant effect group was found for both frequency and satisfaction with leisure.

b) Stressors

Regarding objective stressors, the MANOVA analyses using the 4-group categorization showed a significant main effect of group ($F = 1.98$; $p <.05$). A significant

main effect of group (ANOVA) was found for frequency of behavioral problems. Specifically, the LFLS group had significantly higher scores on frequency of behavioral problems than the LFHS ($p < .001$) and HFHS ($p < .001$) groups. No group effects were found for time caring, daily hours caring and care-recipient´s functional capacity. The effect size was large for frequency of behavioral problems ($\eta p^2 = .21$).

c) Resources variables

A significant main effect of group on emotional regulation strategies was also found ($F = 10.80$; $p < .001$). Significant group effects were found for both rumination and cognitive reappraisal. Particularly, the HFHS group scored significantly lower in rumination than the other three groups (LFLS/LFHS/HFLS) ($p < .05$). In addition, the LFLS group scored significantly higher in rumination than the LFHS ($p < .001$) and HFHS ($p < .001$), and there was a trend to score higher than the HFLS group ($p = .06$).

Regarding cognitive reappraisal, the LFLS group had significantly lower scores on this variable than the LFHS ($p < .05$) and HFHS ($p < .001$) groups. In addition, the HFHS group scored significantly higher in this variable than the HFLS group ($p < .001$). The effect sizes were large for both rumination ($\eta p^2 = .44$) and cognitive reappraisal ($\eta p^2 = .30$).

d) Outcome variables

The results of the MANOVA for outcome variables were also significant ($F = 7.38$; $p < .001$). Significant group effects for all the assessed outcome variables have been found. Specifically, the LFLS group had significantly higher levels of depression (for all groups; $p < .001$) and poorer levels of perceived health (for the LFHS and HFHS groups, $p < .001$; for the HFLS, $p < .05$) than the other three groups. Also, the LFLS group scored

significantly higher in anxiety ($p < .001$) than the LFHS and HFHS groups. Additionally, the HFHS group had lower scores on depression ($p < .001$) and anxiety ($p < .001$) than the HFLS group. The effect sizes were large for depression ($\eta p^2 = .44$), anxiety ($\eta p^2 = .37$) and perceived health ($\eta p^2 = .23$).

e) Risk of institutionalization

Finally, a significant main effect of group was found for risk of institutionalization ($F = 3.27$; $p < .05$). The HFHS group had significantly lower scores on risk of institutionalization than the LFLS ($p < .05$) and the HFLS ($p < .05$) groups. The effect size was large for this variable ($\eta p^2 = .19$).

7.6 Discussion

The principal aim of this study was to analyze differences in key variables (the stress and coping domains and risk of institutionalization) between caregivers' profiles on both reported frequency of and satisfaction with leisure. Taken together, the obtained results are consistent with previous studies (Loucks-Atkinson, Douglas & Williamson, 2006; Mausbach et al., 2007, 2008), showing that having higher levels of both frequency and satisfaction with behavioral activation benefits caregiving (Losada et al., 2010; Mausbach et al., 2008), given that these variables are related with the use of more adaptive emotional regulation strategies, and attenuate caregivers' distress. Specifically, the obtained results showed that caregivers with higher scores on both frequency of/and satisfaction with leisure also reported lower levels of depression and anxiety, and better perceived health, as well as, lower scores on rumination and higher levels of cognitive reappraisal.

Regarding caregivers profiles on frequency and satisfaction with leisure, the obtained results showed that the LFLS (low frequency and low satisfaction with leisure) caregiver group used less adaptive emotional regulation strategies and presented higher levels of caregiver distress, as compared to the other groups. Specifically, the LFLS group showed higher levels of rumination and lower levels of cognitive reappraisal than the other groups. Additionally, this group (LFLS) reported higher levels of depression, anxiety and lower levels of perceived health as compared to the other groups. These results are similar to those found by Mausbach et al. (in press), who found that caregivers with low frequency of pleasant events and high levels of activity restriction reported higher levels of depression, negative affect and overload, and lower levels of personal mastery and self-efficacy than caregivers with high frequency of pleasant events and low activity restriction or with either both high pleasant events and high activity restriction or both low pleasant events and low activity restriction (Mausbach et al., in press).

In addition, results showed that the LFLS group reported a higher frequency of behavioral problems, as compared to the LFHS (low frequency and high satisfaction with leisure) and HFHS (high frequency and high satisfaction with leisure) groups. No differences between LFLS and HFLS in frequency of behavioral problems were found, suggesting that the negative association between frequency of behavioral problems and satisfaction with leisure is independent from the frequency of pleasant activities.

Additionally, the results of this study showed that those caregivers with high frequency and high satisfaction with leisure (HFHS) were more likely to be males and older than the other groups. This group (HFHS) also reported lower scores on rumination, depression, anxiety than those caregivers with low levels of both frequency and satisfaction with leisure (LFLS), and, furthermore, they had less risk of institutionalization as compared to the LFLS group.

It is important to note that our study added to the Mausbach et al. (in press) study the consideration of two additional groups based on caregivers profile on frequency and satisfaction with leisure. The consideration of these additional groups leaded to interesting findings, namely, that among caregivers with low levels of behavioral activation, only those who also report low levels of satisfaction show greater levels of distress and are at risk of regulating their emotions in a dysfunctional way, and that, among those caregivers with high levels of behavioral activation, only those with high levels of satisfaction with it showed better psychological resources and lower distress. Specifically, caregivers who engaged in high levels of leisure and reported high levels of satisfaction with leisure (HFHS) reported lower levels of depression, anxiety and risk of institutionalization, a lower use of rumination and a higher use of reappraisal strategies than those caregivers with high levels of leisure and low levels of satisfaction with leisure (HFLS). It might be that engagement in high levels of leisure activities and reporting better emotional regulation strategies (low rumination and high cognitive reappraisal) fosters caregiver' satisfaction with leisure, which may contribute to explain reductions on caregiver' distress. However, the cross-sectional nature of the study does not allow us to confirm which are the precise directions of the relationships between different coping and outcome variables.

It would be interesting to analyze if reporting higher levels of behavioral and/or satisfaction with leisure leads to using better emotional regulation strategies (e.g. low rumination and high cognitive reppraisal) which repercutes on caregivers' distress, or if the higher use of maladaptative emotional regulation contributes to a lesser frequency and satisfaction with leisure. In this sense, one of the ways that has been suggested in non-caregiver population is that rumination reduces motivation to initiative instrumental behavior (e.g. pleasant actitivities) leading to increases in depression (Nolen-Hoeksema,

Wisco & Lyubomirsky, 2008). Nevertheless, longitudinal and experimental studies are needed in order to improve our knowledge of these issues.

The results of this study reinforce the importance of simultaneously considering caregivers' frequency of/ and satisfaction with leisure. The joint consideration of these two dimensions of leisure may be useful in order to identify those caregivers who may be at greater risk of suffering negative outcomes due to caregiving, as it follows from the obtained associations of the specific leisure profiles with the variables that have been assessed. Specifically, our results suggest that those caregivers reporting at the same time low frequency and low satisfaction with leisure may be at special risk, given that they also report using more frequently than the other groups maladaptive emotional regulation strategies (more rumination and less cognitive reappraisal). The fact that they do and enjoy less leisure activities, and also use more maladaptive emotion regulation strategies, may explain why they also report higher levels of distress.

In addition, this study adds to previous research the analysis of the effect that leisure profile has on caregivers' risk of institutionalizating their relatives. Consistently with our expectations, results indicate that both frequency and satisfaction with leisure were negatively associated with caregivers' desire of institutionalization. This study highlights the importance of leisure (frequency and satisfaction) for the continuation of caregiving at home, given the obtained finding that caregivers with HFHS report lower scores on desire to institutionalize their relatives. Hence, it seems that having high levels of behavioral activation may not be enough to prevent risk of institutionalization, as it is also important to be satisfied with activities. This finding suggests that training caregivers in behavioral and satisfaction activation techniques (Burgio, Stevens, Guy, Roth & Haley, 2003; Gallagher-Thompson et al., 2000) may contribute to prevent risk of institutionalization (or to delay the desire of institutionalization).

Furthermore, more research analyzing which variables mediate the relationship between frequency of pleasant events and satisfaction with them is needed. Future studies are required to explore the possible reasons explaining that caregivers´ satisfaction with leisure activities varied independently of their frequency of realization of these activities. It seems especially interesting to analyze why some caregivers report a high frequency of pleasant events but low satisfaction with them, and, also, why some caregivers report a low frequency of pleasant events but high satisfaction with them. One explanation may be related with the caregivers' expectations (e.g. unrealistic or perfectionist goals) about the frequency of pleasant activities or the joy/pleasure with leisure they should or are (socially) expected to have. Some caregivers can engage in pleasant activities, but may find difficult to enjoy them because they are not able to mentally disengage from their caregiving obligations or feel guilty about devoting leisure time to theirselves (Losada et al., 2010). Dysfunctional beliefs about what does it mean to be a good caregiver may also interfere with the enjoyment of leisure time (Márquez-González, Losada, Izal, Pérez-Rojo, Montorio, 2007). In other cases, a caregiver may desire to do many leisure activities, which is a difficult goal to achieve, given the high number of caregiving demands. The result in this case may likely be that these caregivers, even when they engage in some activities, will find their expectations frustrated and, hence, they will not be satisfied regarding their leisure. This is consistent with a study done by Lund et al. (2009), who found that those caregivers who were inconsistent in their desired versus actual respite activities, and were also dissatisfied with their use of time, were more depressed and reported more negative scores on burden dimensions as well as less satisfaction with caregiving. Another possible explanation of the asynchrony between frequency and satisfaction with leisure may be related with the use of emotional regulation strategies. In this sense, results suggested that the LFLS group used poorer emotional regulation

strategies than the LFHS group, as they reported significantly higher levels of rumination and lower levels of cognitive reappraisal, suggesting that the more caregivers ruminate, and the less they use cognitive reappraisal, the more difficult is for them to enjoy leisure activities.

Regarding gender differences in the leisure profile, we have found that it is more likely that men with high levels of frequency of pleasant events also report high levels of satisfaction with them. Conversely, the profile defined by a high frequency of pleasant activities and low levels of satisfaction with them is more likely to be found among women. This finding might be explained by taking into account that female caregivers report greater number of caregiving hours, caregiving tasks and role conflict than males (Pinquart and Sörensen, 2006), circumstances that might interfere with the enjoyment of leisure time. Other possible explanation may be related to the greater levels of guilt about neglecting other relatives reported by females (Losada et al., 2010), which may explain why, even though they engage in leisure activities, they do not enjoy them because they have guilt-related thoughts such as "I should be looking after my other relatives".

The results of this study have several clinical implications. First, the analysis of the leisure profile may provide relevant information to help clinicians and policy makers to tailor interventions to match caregivers´ specific profile. For example, caregivers with LFLS may be those caregivers at greater risk of health problems and could benefit more from interventions aimed at fostering behavioral activation, such as training them in better coping skills that could help them increase the number of leisure activities (see studies, Gallagher-Thompson et al., 2003; Gallagher-Thompson et al., 2002; Losada, Márquez-González, and Romero-Moreno, in press). However, our results highlight the importance of focusing not only on increasing caregiver frequency of leisure actitivities but also on their levels of satisfaction with them. Although increase of behavioral activation has been

considered as a key component in psychological interventions to improve distress (e.g., Cuijpers, van Straten, and Warmerdam, 2007; Jacobson et al., 1996), more caution should be taken by therapists in order to activate those leisure activities related with caregivers´ personal values, so that they can obtain a sense of purpose and fulfilment which facilitate their satisfaction with leisure. The new therapeutical approach called 'Acceptance and Commitment Therapy' may be a useful tool to achieve these objectives, as their main treatment goals are fostering caregivers´ commitment with their personal values, encouraging them to engage in actions that help them get closer to these values, and promoting caregivers´ acceptance of negative internal events (e.g. feelings and thoughts) (Márquez-González, Romero-Moreno & Losada, in press).

Caregivers showing other frequency and satisfaction profiles may also benefit from interventions. For example, caregivers showing a HFHS could benefit of respite interventions that could provide them enough time to continue doing leisure activities. In this regard, results must be interpreted cautiously as, even though there were no significant differences between groups in hours/day caring, the lack of statistical control of the amount of caregivers' service use (e.g. day care centers) may influence caregivers frequency of leisure profile.

Some limitations of this study have to be considered. As it has been commented above, the cross-sectional nature of this study prevents us from doing causal inferences. In addition, the caregiver sample consisted of caregivers recruited through social and day care centers who volunteered to participate in the study, and so the results may not be generalizable to the whole caregiver population (Pruchno et al., 2008).

In summary, the results of this study suggest that both frequency of/ and satisfaction with leisure have positive effects on the caregivers stress and coping process, as it follows from their association with adaptive emotional regulation strategies and

positive caregiving outcomes. Moreover, this study highlights the benefits of analyzing simultaneously, rather than separately, the effects of frequency of/ and satisfaction with leisure on caregivers distress. Finally, this analysis has shown to provide empirical support for the PEAR ("Pleasant Events and Activity Restriction") model (Mausbach et al., in press).

7.7 References

Aldao, A., Nolen-Hoeksema, S., & Schweizer, S. (2010). Emotion-regulation strategies across psychopathology: A meta-analytic review. *Clinical Psychology Review, 30*, 217-237.

Benyamini, Y., & Lomranz, J. (2004). The relationship of activity restriction and replacement with depressive symptoms among older adults. *Psychology and Aging, 19,* 362-366.

Burgio, L., Stevens, A., Guy, D., Roth, D.L., & Haley, W.E. (2003). Impact of two psychological interventions on White and African American Family Caregivers of Individuals with Dementia. *The Gerontologist, 43,* 568-579.

Croezen, S., Haveman-Nies, A., Alvarado, V.J., Van`T Veer, P., & De Groot, C.P. (2009). Characterization of different groups of elderly according to social engagement activity patterns. *The Journal of Nutrition Health and Aging, 13,* 776-781.

Cuijpers, P., van Straten, A., & Warmerdam L. (2007). Behavioral activation treatments of depression: a meta-analysis. *Clinical Psychology Review, 27,* 318-326.

Gallagher-Thompson, D., Coon, D.W., Solano, N., Ambler, C., & et al. (2003). Change in indices of distress among Latino and Anglo female caregivers of elderly relatives with dementia: Site-specific results from the REACH national collaborative study. *The Gerontologist, 43*, 580-91.

Gallagher-Thompson, D., Lovett, S., Rose, J., McKibbin, C., Coon, D., Futterman, A., & Thompson, L.W. (2000). Impact of psycho-educational interventions on distressed family caregivers. *Journal of Clinical Geropsychology, 6,* 91-110.

Haley, W.E., Levine, E.G., Brown, L., & Bartolucci, A.A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia

caregivers. *Psychology and Aging, 2,* 323-330.

Hirano A., Suzuki, Y., Kuzuya, M., Unishi, J., Hasegawa, J., Ban, N., & Umegaki, H. (in press). Association between the caregivers' burden and physical activity in community-dwelling caregivers of dementia patients. *Archives of Gerontology and Geriatrics.*

Jackson, B. and Nolen-Hoeksema, S. (1998). *The Emotion-Focused Coping Questionnaire.* Manuscript in progress.

Jacobson, N.S., Dobson, K.S., Truax, P.A., Addis, M.E., Koerner, K., Gollan, J.K., et al. (1996). A component analysis of cognitive-behavioral treatment for depression. *Journal of Consulting and Clinical Psychology, 64,* 295-304.

Knight, B.G., & Sayegh, P. (2010). Cultural values and caregiving: the updated Sociocultural Stress and Coping Model. *Journal of Gerontology: Psychological Sciences, 65,* 5-13.

Lewinsohn, P.M. (1975). Engagement in pleasant activities and depression level. *Journal of Abnormal Psychology, 84*, 729-731.

López J., López-Arrieta, J., & Crespo, M. (2005). Factors associated with the positive impact of caring for elderly and dependent relatives. *Archives of Gerontology and Geriatrics, 41,* 81–94.

Losada, A., Márquez-González, M., & Romero-Moreno, R. (in press). Mechanism of action of a psychological intervention for dementia caregivers: effects of behavioural activation and dysfunctional thoughts modification. *International Journal of Geriatric Psychiatry.*

Losada, A., Márquez-González, M., Peñacoba, C., & Romero-Moreno, R. (2010). Development and validation of the Caregiver Guilt Questionnaire. *International Psychogeriatrics, 22,* 650-660.

Losada, A., Pérez-Peñaranda, A., Rodríguez, E., Gómez, M.A., Ballesteros, C., Ramos, I., Campo, M.A. & García, L. (2010). Leisure and distress in caregivers for elderly patients. *Archives of Gerontology and Geriatrics, 50*, 347-350.

Loucks-Atkinson, A., Douglas, A., & Williamson, G.M. (2006). Activity restriction and well-being in middle-aged and older caregivers. *Topics in Geriatric Rehabilitation, 22,* 269-282.

Lund, D.A., Utz, R., Caserta, M.S., & Wright, S.D. (2009). Examining what caregivers do

during respite time to make respite more effective. *Journal of Applied Gerontology, 28,* 109-131.

Mahoney, F.L. & Barthel, D.W. (1965) Funcional evaluation: The Barthel Index. *State Journal, 4*, 61-65.

Márquez-González, M., Losada, A., Izal, M., Pérez-Rojo, G. & Montorio, I. (2007). Modification of Dysfunctional Thoughts about Caregiving in Dementia Family Caregivers: description and outcomes of an Intervention Program. Aging & Mental Health, 11**,** 616-625.

Márquez-González, M., Romero-Moreno, R. and Losada, A. (in press). Caregiving issues in a therapeutic context: new insights from the Acceptance and Commitment approach. In K. Laidlaw and N. Pachana, (Eds.). *Casebook of Clinical Geropsychology: International Perspectives on Practice*. New York: Oxford University Press.

Mausbach B.T., Coon, D.W., Patterson, T.L., & Grant, I. (2008). Engagement in activities is associated with affective arousal in Alzheimer´s caregivers: a preliminary examination of the temporal relations between activity and affect. *Behavior Therapy, 39,* 366-374.

Mausbach, B.T., Cardenas, V., Goldman, S., & Patterson, T. (2007). Symptoms of psychosis and depression in middle-aged and older adults with psychotic disorders: the role of activity satisfaction. *Aging and Mental Health, 11,* 339-345.

Mausbach, B.T., Patterson, T.L., & Grant, I. (2008). Is depression in Alzheimer's caregivers really due to activity restriction? A preliminary meditational test of the Activity Restriction Model. *Journal of Behavior Therapy and Experimental Psychiatry, 39,* 459-466.

Mausbach, B.T., Roepke, S.K., Depp, C.A., Moore, R., Patterson, T.L., & Grant, I. (in press). Integration of the Pleasant Events (PE) and Activity Restriction (AR) Models: Development and Validation of a "PEAR" Model of Negative Outcomes in Alzheimer´s Caregivers. *Behavior Therapy.*

Mausbach, B.T., Roepke, S.K., Depp, C.A., Patterson, T.L., & Grant, I. (2009). Specificity of cognitive and behavioral variables to Positive and Negative Affect. *Behaviour Research and Therapy, 47,* 608-615.

McNair, D., Lorr, M. and Droppleman, L. (1971). *Profile of Mood States. Manual*. San

Diego: Educational and Industrial Testing Service.

Nolen-Hoeksema, S., Wisco, B.E., & Lyubomirsky , S. (2008). Rethinking rumination. *Perspectives on Psychological Sciences, 3,* 400-424.

Pinquart, M., & Sörensen, S. (2003). Differences between Carevigers and noncarevigers in psychological health and physical health: a meta-analysis. *Psychology and Aging 18,* 250-267.

Pinquart, M., & Sörensen, S. (2006). Gender Differences in Caregiver Stressors, Social Resources, and Health: An Updated Meta-Analysis. *Journal of Gerontology: Psychological Sciences, 61,* 33-45.

Pruchno, R., Brill, J., Shands, Y., Gordon, J., Genderson, M., Rose, M., & Cartwright, F. (2008). Convenience Samples and Caregiving Research: How Generalizable Are the Findings? *The Gerontologist, 48*, 820-7.

Radloff, L.S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1,* 385-401.

Raes, F., Hoes, D., Van Gucht D., Kanter, J.W., & Hermans, D. (2010). The Dutch version of the behavioral activation for depression scale (BADS): Psychometric properties and factor structure. *Journal of Behavior Therapy and Experimental Psychiatry, 41,* 246-250.

Raj, J.P., Manigandan, C., & Jacob, K.S. (2006). Leisure satisfaction and psychiatric morbidity among informal carers of people with spinal cord injury. *Spinal Cord, 44,* 676-679.

Salovey, P., Mayer, J.D., Goldman, S.L., Turvey, C. and Palfai, T.P. (1995). Emotional attention, clarity, and repair: Exploring emotional intelligence using the Trait Meta-Mood Scale. In J.W. Pennebaker, (Eds). *Emotion, Disclosure, and Health* (pp.125-154). Washington, D.C.: American Psychological Assn.

Stevens, A.B., Coon, D., Wisniewski, S., Vance, D., Arguelles, S., Belle, S., Mendelsohn, A., Ory, M. y Haley, W. (2004). Measurement of leisure time satisfaction in family caregivers. *Aging and Mental Health, 8*, 450-459.

Tabachnick, B.G. and Fidell, L.S. (1996). *Using multivariate statistics* (3rd ed.). New

Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S. and Vitaliano, P.P. (1992). Assessment of Behavioral Problems in Dementia: The Revised Memory and Behavior Problems Checklist. *Psychology and Aging, 7,* 622-631.

Thompson, L.W., Solano, N., Kinoshita, L., Coon, D. W., Mausbach, B., & Gallagher-

Thompson, D. (2002). Pleasurable activities and mood: Differences between Latina and Caucasian dementia caregivers. *Journal of Mental Health and Aging, 8,* 211-224.

Vitaliano, P.P., Young, H.M., & Zhang, J. (2004). Is caregiving a risk factor for illness? *Current Directions in Psychological Science, 13*, 13-16.

Warr, P., Butcher, V., & Robertson, I. (2004). Activity and psychological well-being in older people. *Aging and Mental Health, 8,* 172-183.

Williamson, G.M., & Schulz, R. (1992). Pain, activity restriction, and symptoms of depression among community-residing elderly adults. *Journal of Gerontology: Psychological Sciences, 47,* 367-372.

Williamson, G.M., & Shaffer, D.R. (2000). The activity restriction model of depressed affect: Antecedents and consequences of restricted normal activities. In G.M. Williamson, D.R. Shaffer & P.A. Parmelee (Eds.), *Physical Illness and depression in older adults: A handbook of theory, research, and practice* (pp. 173-200). New York: Kluwer Academic/Plenium. York: Harper Collins

4

ESTUDIO CUATRO

VARIABLES MODULATING DEPRESSION IN DEMENTIA CAREGIVERS: A LONGITUDINAL STUDY

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8. Estudio Cuatro: Variables modulating depression in dementia caregivers: a longitudinal study

8.1 Abstract

Introduction

Dementia caregiving has been linked to negative consequences for mental health in caregivers. Although depression seems to be an enduring psychological consequence associated with caregiving, little is known about the longitudinal effects that modulating variables related to coping strategies have on caregiver's changes in depression over time.

Objective and method

To analyze, in a one year longitudinal study with 190 dementia caregivers, if change in caregivers' depression scores can be predicted by changes in modulating variables (self-efficacy for controlling upsetting thoughts, frequency of leisure activities and cognitive reappraisal) scores, after controlling for gender and caregivers' stressors (frequency of behavioral problems). Random regression was used to analyze the associations between time-varying values for caregiver' stressors and modulating variables in predicting caregivers' depression.

Results

It was found that increases in caregiver' self-efficacy, frequency of leisure activities and cognitive reappraisal significantly predicted decreases in caregiver' depression over time, even after controlling for gender and frequency of behavioural problems. In addition, increases in stressors were significantly related with increases in depression over time.

Conclusion

The inclusion of modulating variables (selfefficacy, behavioral activation and cognitive reappraisal) significantly contributed to the explanation of the variance in caregivers´

depression, adding explanatory power to the variables usually included in the stress and coping model (gender and stressors).

Keywords: dementia caregivers, depression, behavioral activation, self-efficacy, cognitive reappraisal, caregiving stress and coping

8.2 Introduction

8.2.1 The Stress and Coping Model

As it is widely documented, being a caregiver of people with dementia is associated with negative consequences for caregiver's physical and mental health (e.g. Pinquart and Sörensen, 2003). Considering the strong demands that caregivers have to cope with during a long period of time, it is not surprising that dementia caregiving has been considered as a prototypical example of chronic stress situations (Vitaliano, Young and Zhang, 2004), being the stress and coping model adapted to caregiving the theoretical model mostly used for understanding caregiving distress (Haley, Levine, Brown and Bartolucci, 1987). Following this model, although caregivers must face similar situations, they differ from each other in their mental health outcomes (e.g. depression), as the impact that objective stressors (e.g. care-recipient's frequency of behavioral problems) have on caregiver's health depends on modulating variables (e.g. caregiver's appraisals and coping strategies). Among the most widely analyzed modulating variables in caregiving research are social support and coping strategies (e.g. Gotlieb and Rooney, 2004; Schulz, O´Brien, Bookwala and Fleissner, 1995). The benefits that other psychological variables, such as caregiver's cognitive and behavioural resources (e.g. caregiver's self-efficacy and leisure activities) have on caregiver's distress have been also reported (Mausbach et al., 2009; Romero-Moreno et al., 2010).

8.2.2 Stability of caregivers' distress over time

Although the vas majority of studies on caregiving distress are cross-sectional, longitudinal support for the negative effects of dementia caregiving on caregivers' outcomes has also been found, showing that being a caregiver is linked with suffering higher distress than non care-givers (Joling et al., 2010). In addition, studies that have

been focused on following-up caregiver's distress (e.g. depression or burden) during a specific period of time (Arai, Zarit, Sugiura and Washio, 2002; Heru & Ryan, 2006; Taylor et al., 2008; Wright, 1994), have shown its stability over time (Clay, Roth, Wadley and Haley, 2008; Gaugler, 2010; Gaugler et al., 2005; Schulz & Williamson, 1991). However, decreases on caregivers' depression over time have also been reported (Berger et al., 2005). Although women have been found to report higher levels of depression (Schulz and Williamson, 1991) and higher prevalence of depressive disorders (Cuijpers, 2005) and strain (Lyons, Stewart, Archbold & Carter, 2009) than men, men seem to be more likely than women to experience increases in symptoms of depression over time (Schulz and Williamson, 1991).

8.2.3 Consequences of caregivers' depression over time

The importance of analyzing caregivers' depression is supported by findings showing that increases in depression over time are associated with a decline in health status and an increased risk of death or stroke or myocardial infarction (Mausbach, Patterson, Rabinowitz, Grant & Schulz, 2007; O'Rourke, Cappeliez & Neufeld, 2007). Particularly, it has been found that 5-unit increase in the CES-D (Center for Epidemiological Studies-Depression; Radloff, 1977) was predictive of a 25% increased risk of death in older people (Wassertheil-Smoller et al., 1996) and of a 20% increased risk of cardiovascular disease in dementia caregivers (Mausbach et al., 2007). Additionally, it has been found that changes in caregiver's distress over time do not only have negative consequences for caregivers, but also for care-recipients: increases in caregiver's depression over time predict significant increases in reported caregiver's abuse behaviours toward the person they were caring for (Cooper, Blanchard, Selwood, Zuzana

& Livingston, 2010) and increases in care-recipient's risk of institutionalization (Coehlo, Hooker and Bowman, 2007).

8.2.4 Relationship between caregivers' stressors and distress over time

On the other side, longitudinal caregiving studies have been focused on analyzing the impact that caregiver' stressors (e.g. frequency of behavioral problems or burden) have on caregivers' mental and physical health (Danhauer, McCann, Gilley, Beckett, Bienias & Evans, 2004; Epstein-Lubow, Davis, Miller & Tremont, 2008; Gaugler, Kane, Kane & Newcomer, 2005), showing a general negative effect of stressors on caregiver's outcomes. In this sense, it has been found that increases in caregivers' stressors (e.g. caregiving involvement or burden) were associated with increases in caregivers' distress (e.g. depression), even after controlling for sociodemographic characteristics (Ballard, Eastwood, Gahir and Wilcock, 1996; Beach et al., 2000; O'Rourke & Tuokko, 2004). However, no associations between caregivers' stressors (e.g. frequency of behavioural problems) and their levels of depression have also been reported (Schulz and Williamson, 1991; Shaw et al., 1997), suggesting that further longitudinal studies are needed (Black and Almeida, 2004).

8.2.5 Relationships between modulating variables and caregivers' distress over time

Regarding the analysis of the longitudinal effects of modulating variables on caregivers' distress, caregiving research is sparse. Li, Seltzer and Greenberg (1999) found that using problem-focused coping strategies -composed by a summed score of different strategies such as active coping, planning, positive reinterpretation and suppression of competing activities-significantly predicted reductions in depressive symptoms over time.

Cooper et al. (2008) found that using fewer emotion focused strategies (based on acceptance, humor, positive reframing and religion scores) predicted higher psychological morbidity (anxiety). With regard to the longitudinal effects of specific modulating variables on caregiver' distress, available data show that variations in personal mastery, perceived social support and satisfaction with social support over time were significantly and negatively related to caregiver' depressive symptoms in dementia caregivers (Clay, Roth, Wadley and Haley, 2008; Mausbach et al., 2007; Schulz and Williamson, 1991).

To our knowledge, no longitudinal studies framed in the stress and coping model (e.g., Haley et al., 1987) analyzing the impact of specific modulator variables on caregivers' distress, after controlling for key variables (gender and stressors), are available. Specifically, no longitudinal data linking caregivers' perceived self-efficacy or caregivers' behavioral activation with caregivers' distress are available, in spite of the cross-sectional empirical support for the benefits of these variables on caregiving distress (Márquez-González et al., 2009; Mausbach et al., 2009; Romero-Moreno et al., in press). The aim of this study is to analyze co-variations between specific modulator variables (self-efficacy, behavioral activation and cognitive reappraisal) and caregivers' depression, after controlling for gender and frequency of behavioral problems. Drawing upon the stress and coping model (Haley et al., 1987), we hypothesized that increases in stressors and decreases in modulating variables (self-efficacy for controlling upsetting thoughts, frequency of leisure activities and cognitive reappraisal) would co-vary with increases in depression over time. Also, we hypothesized that the inclusion of modulating variables into the final model would contribute to a significant increase in the percentage of variance explained of caregivers' changes in depression over time. Finally, considering previous studies, significant gender differences in changes in depression over time were predicted, with higher increases expected for male caregivers.

8.3 Methods

8.3.1 Participants

Participants in this study were 190 caregivers of relatives with dementia. All caregivers were caring for relatives living in the community. The inclusion criteria to participate in this study were: identifying oneself as the main source of help for their relatives, reporting that more than one hour per day was devoted to caregiving duties, and providing care for more than three consecutive months. Baseline characteristics of the sample are shown in Table 8.1.

Table 8. 1. Demographic characteristics at baseline.

Characteristic	M	SD	Range	%	n
Gender (female)				81.10	154
Kinship to the care-recipient					
Spouses				34.74	66
Parent				59.47	113
Others				5.79	11
Caregiver's age	59.75	12.37	29-87		
Daily hours caregiving	10.99	7.64	1-24		
Time spent caregiving (months)	57.41	47.74	3-312		
Care-recipient age	79.03	7.59	48-97		
Frequency of behavioral problems	36.00	14.90	1-83		
Cognitive reappraisal	6.32	3.37	0-12		
Self-efficacy	288.32	139.37	0-500		
Pleasant activities	8.46	4.31	0-20		
Depression	18.00	11.96	0-52		

8.3.2 Procedure

Participants were recruited into a study of psychosocial consequences of caregiving stress and development of psychoeducational interventions for caregivers (Losada, Márquez-González, and Romero-Moreno, in press; Romero-Moreno et al., in press) through various Social and Day Care centers from Madrid (Spain) and via

announcements in the media. In order to check whether caregivers met the inclusion criteria, participants were initially contacted by telephone. Subsequently, face-to-face interviews were conducted in the different centers involved in the study. Over the course of the study, 3 assessments were conducted: at baseline, at the 3-months follow-up and 1 year follow-up from baseline. All participants provided informed consent to enter into the study. Both the Spanish Ministry of Education and the Ethical Committee from the Universidad Rey Juan Carlos gave their approval for the study.

8.3.3 Measures

In addition to sociodemographic information at baseline (see Table 8.1), the following variables were assessed:

a) Stressors

Frequency of behavioral problems. The Revised Memory and Behavior Problems Checklist (Teri et al., 1992) was used. This is a 24 item-scale that assesses the frequency of behavioural problems in dementia patients (e.g., "During the past week, how often did your relative lose or misplace things?"). Scores range from 0 = "not at all" to 4 = "extremely". Internal consistency (Cronbach alpha) of this scale in this study was .82.

b) Modulating variables

Cognitive reappraisal. This variable was assessed selecting four items from the Mood Repair subscale from the Trait Meta-Mood Scale (TMMS-24; Salovey, Mayer, Goldman, Turvey and Palfai, 1995), which assess cognitive reappraisal, this is, the cognitive ability to change thoughts in a positive way in order to repair unpleasant moods (e.g. "When I become upset, I remind myself of all the pleasures in life"). Scores range

from 0 = “never” to 3 = “always”. The internal consistency (Cronbach’s alpha) of this scale in the present study was .84.

Self-efficacy. The Self-efficacy for Controlling upsetting thoughts subscale from the Revised Scale for Caregiving Self-efficacy (Steffen et al, 2002) was used. Particularly, the Spanish version of the scale was used (Marquez-Gonzalez et al., 2009). It consist of 5 items that assess the confidence that the caregiver can turn off or get rid of different type of negative thoughts when it does come up (e.g. “How confident are you that you can control thinking about unpleasant aspects of taking care of ____?”), with scores ranging from 0 = “can not to do at al” to 100 = “certain can do”. In this study, the subscale presents an internal consistency of .78 (Cronbach alpha).

Behavioral activation. An adaptation of the Leisure Time Satisfaction measure (Stevens et al., 2004) was used. It consists of 6 items that assess how often the person engaged in different pleasant events over the past month (e.g. “How often did you go out for meals or other social activities”?). Scores range from 0 “not at all” to 4 “a lot”. In this study, the internal consistency (Cronbach alpha) was .70.

c) Outcome variable

Depression. The Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977) was used. This scale consists of 20 items assessing the frequency of depressive symptoms during the previous week (e.g. “I thought my life had been a failure”). Scores range from 0 “rarely or none of the time” to 3 “most or all the time”. In the present study the internal consistency (Cronbach’s alpha) for the scale was .90.

8.4 Data analysis

In order to examine the impact of predictors on depression over time, linear mixed-effects regression models were used. Mixed model regression allows us to estimate an intercept and slope for each participant based on all available data for that individual, augmented by the data from the entire sample. Hence, as missing data are common at one or more times-points in longitudinal studies, the use of mixed models allows individual slopes to be estimated using the available data for that participant.

With the aim of increasing interpretability of regression coefficients and diminishing problems associated with multicollinearity, the linear variables (frequency of behavioral problems, cognitive reappraisal, pleasant activities and self-efficacy) were centered at their grand means following Kraemer and Blasey (2004) recommendations. The mixed regression model included depression as the dependent variable and stressors (frequency of behavioral problems) and modulating variables (cognitive reappraisal, pleasant activities and self-efficacy) as time-varying covariates. In addition, the model included the time invariant main effect for gender which was dummy coded as "0" = men and "1"= women. Because participation or not in the intervention that was carried out in this study (see Losada et al., in press) can have an influence on depression' changes over time, this variable was controlled in statistic analyses. In order to control for treatment effect described above, time, treatment condition and the "time X treatment condition" interaction were entered in the model. Specifically, time was coded as "0" = baseline scores, "1" = 3 months after (post-treatment) and "2"= one year follow-up from baseline. Treatment condition was coded as"0" = control group and "1" = intervention group. As the treatment condition was coded as "0" = control group and "1" = treatment group, the estimate for "time" represented the slope for caregivers in the control group and the corresponding p value indicated whether this slope was significant. The "time X treatment

condition" interaction estimate represented the differential in slope for caregivers. Finally, the model included random intercepts and slopes and Akaike's Information Criteria (AIC) was used to achieve for the final model fit using an unstructured covariance matrix.

8.5 Results

8.5.1 Dropouts/Missing Data

Of the 190 participants enrolled in the study (48,42% caregivers were randomly assigned to a control group; see Losada et al., in press for a description of the allocation process), data were available for 117 caregivers (41,74% of caregivers in the control group) at the 3-months follow-up. At the 1-year follow-up assessment, data were available for 84 caregivers (24,66% caregivers control group). In order to test if missing data occurred at random, several analyses were conducted. First, in order to analyze differences between caregiver males and females in missing data at any of the assessments, Fisher's tests were conducted. Missing data differences between males and females were not found at any time point, as per Fisher's exact test results showed that 55.56% of males and 57.14% of females missed the 3-months follow-up ($p = .50$), and 44.44% of males and 37.01% of females missed the 1-year follow-up assessment ($p = .26$). In addition, in order to analyze differences between those caregivers who missed an assessment and those who did not miss any of the assessed variables, independent samples t-tests were conducted. Specifically, there were no significant differences between those caregivers who missed the 3-months follow-up and those who did not in their scores on depression ($t = -1.01$; $p = .33$), frequency of behavioral problems ($t = .26$; $p = .80$), cognitive reappraisal ($t = 1.24$; $p = .31$), behavioral activation ($t = 1.03$; $p = .31$) and self-efficacy ($t = .24$; $p = .86$); and at the 1-year follow-up assessment on depression ($t = .76$; $p = .45$), anxiety ($t = .48$; $p = .63$), frequency of behavioral problems ($t = -.41$; $p = .68$), cognitive reappraisal ($t = .12$; p

=.90), behavioral activation (t = .94; p = .35) and self-efficacy (t = -.24; p =.81). Caregivers who missed the 1-year follow-up assessment showed significantly higher levels of behavioral activation at baseline (t = 2.07; p <. 05), as compared to caregivers who did not miss that assessment. In addition, those caregivers who missed the 1-year follow-up showed significantly lower levels of behavioral activation (t = -2.14; p < .05) and higher levels of depression (t = 2.83; p < .01) at the 3-months follow-up compared to those who did not. No significant differences were found between caregivers who missed the 1-year follow-up assessment and those who did not in their scores on the rest of the assessed variables at baseline and at the 3-months follow-up (p > .05). Finally, we compared whether caregivers from the control group were more likely to miss an assessment than caregivers from the intervention group. Results showed that caregivers from the control group were significantly more likely to miss an assessment at both the 3-months follow-up (p < .01) and the 1-year follow-up (p < .01).

8.5.2 Change in depression Over Time

The results of the linear mixed model conducted to analyze the relationship between frequency of behavioral problems, cognitive reappraisal, behavioral activation and self-efficacy for controlling upsetting thoughts and depression are shown in Table 8.2.

Table 8. 2. Linear mixed-effects model for depressive symptoms over time.

Variable	Estimate	SE	t	p	df	95% Confidence Interval	
						Lower bound	Upper bound
Intercept	14.03	2.28	6.14	<.001	235.28	9.523	18.53
Time	.65	1.01	.64	.52	149.23	-1.35	2.64
Treatment condition (0 = control group)	3.53	2.36	1.49	.14	156.02	-1.14	8.19
Time × Treatment condition	-2.16	1.21	-1.78	.08	135.98	-4.57	.24
Gender (0 = males)	2.46	1.67	1.47	.14	130.65	-.84	5.76
Frequency of behavioral problems	.12	.035	3.59	<.001	280.93	.06	.19
Cognitive reappraisal	-1.04	.18	-5.89	<.001	306.79	-1.39	-.69
Behavioral activation	-.79	.12	-6.39	<.001	312.18	-1.04	-.55
Self-efficacy	-.01	.00	-3.36	<.001	281.32	-.02	-.01

Intercept corresponds to depression for male's caregivers control group at baseline. Gender was coded as 0 =male, 1 = female; treatment condition was coded as 0 = waiting-list group and 1 = intervention group and time was entered as a linear variable with 0 = baseline scores, 1 = 3 months- follow-up and 2 = one year follow-up from baseline.

The effect of treatment was not significant (t = 1.49; df = 156.02; p =.14), indicating that caregivers in the control group showed no significant differences in depression over time compared to those in the treatment group. The estimate for "time" referred to the slope when treatment condition coded as "0" (the slope for the caregiver's control group). The coefficient for "time" was not significant (t =.64; df =149.29; p = .52), indicating that caregivers in the control group showed no significant changes in depression over time. In addition, the interaction "time X treatment condition" was not significant (t =-1.78; df =135.98; p = .08), indicating that caregivers in the control group did not differ in their slope as compared to those in the intervention group.

Because linear independent variables were centered at their grand means, intercept represents depression scores at baseline for caregivers with average scores in frequency of behavioral problems, cognitive reappraisal, behavioral activation and self-efficacy for controlling upsetting thoughts variables. Results showed that the time-varying

value for frequency of behavioral problems was a significant predictor of depression over time (t =3.59; df = 280.93; p < .001), indicating that those caregivers with higher scores on behavioral problems over time, also reported higher scores on depression over time. In addition, the time-varying value for self-efficacy for controlling upsetting thoughts was a significant predictor of depression over time (t = -3.36; df = 281.32 p < 001), indicating that caregivers with higher scores on this type of self-efficacy over time also had lower scores on depression over time. Also, caregivers who reported higher scores on both pleasant activities (t =-6.39; df = 312.18; p <.001) and cognitive reappraisal over time (t = -5.89; df = 306.79; p <.001) also presented lower levels of depression over time.Because each of these covariates was time-varying, changes in depression in any given assessment were associated with changes in these covariates. For example, in major assessment times when self-efficacy and/or pleasant activities and/or cognitive reappraisal increased and/or frequency of behavioral problems decreased, there were concomitant reductions in depression.

Finally, the effect of gender was not significant (t =.1.47; df =130.65; p = .14), reflecting that male and female caregivers' showed no significant differences in change in depression scores over time.

The overall fit of the model was tested using the Akaike's Information Criteria (AIC), representing smaller values on AIC better-fitting models. Because this value is not intrinsically interpretable and it is useful as a way of comparing models, different models were tested. Results showed that the inclusion of modulating variables (self-efficacy, pleasant activities and cognitive reappraisal) in the final model significantly improved the model beyond that produced by considering treatment effect, gender and frequency of behavioral problems (χ^2 (7) = 2311.97 - 2585.44= 273.47, p <.001). Finally, 52.6% of the between-person variance was explained by the final model.

8.6 Discussion

Following the stress and coping model (e.g. Haley et al., 1987), the purpose of this one- year longitudinal study was to analyze if changes in dementia caregivers' modulating variables (self-efficacy for controlling upsetting thoughts, frequency of leisure activities and cognitive reappraisal) contributed significantly to the prediction of caregivers' changes in depression over time, after controlling for gender and caregiver's stressors (frequency of behavioural problems).

Regarding gender as predictor of caregiver' depression, contrary to our expectations, results suggested non-gender differences in depression over time, although results showed that there was a trend for caregivers women to report higher scores on depression. Consistently with previous longitudinal studies (Gaugler et al., 2005; Perren, Schmid & Wettstein, 2006), the obtained results suggested that frequency of behavioral problems predicted caregiver' depression over time. Specifically, we found that greater increases in the frequency of behavioral problems over time were associated with increases in depression over time. In addition, according to our hypotheses, the results of this study showed that changes in caregivers' modulating variables predicted changes in depression over time, even after controlling for gender and frequency of behavioural problems. Furthermore, our study adds to previous research that the inclusion of time-varying associations between modulating covariates -self-efficacy for controlling upsetting thoughts, behavioral activation and cognitive reappraisal- and caregivers' depression, increased significantly the percentage of variance in caregivers' depression explained by gender and frequency of behavioral problems.

Specifically, the results showed that increases in (caregivers' self-efficacy for controlling upsetting thoughts over time predicted decreases in depression over time,

which is consistent with previous cross-sectional studies (Márquez-González et al., 2009; Romero-Moreno et al., in press; Steffen et al., 2002). However, the results of this study differ slightly from a study conducted by Ducharme, Lévesque, Zarit, Lachance and Giroux (2007) in which they found that an increase in husband caregivers´ self-efficacy did not predicted their psychological distress over a year, although it predicted successful outcomes for self-perceived health. These contradictory results could be explained through between studies differences in caregivers' sample characteristics: the Ducharme et al. (2007) study was conducted with husband caregivers, most of them reporting low scores on psychological distress.

In addition, consistently with other cross-sectional studies (e.g. Losada et al., 2010; Searson, Hendry, Ramachandran, Burns, & Purandar, 2008), the results of this study showed a positive effect of leisure activities on caregiver's distress over time. This study adds to previous research that increases in caregiver's frequency of leisure activities significantly predicted decreases in caregiver's levels of depression. These results seem to be congruent with another longitudinal study that showed that a more frequent use of the coping strategy "maintaining balance" (e.g. "keeping a little free time to my self" or "maintaining interest outside caring") significantly predicted a decrease in caregiver's distress over time (Knussen et al., 2008), and strengthen the consideration of behavioral activation as a potentially effective strategy to reduce caregiver's distress (Losada, Márquez-González & Romero-Moreno, in press). In addition, it would be interesting to analyze if subjective dimensions of leisure (e.g. caregiver's satisfaction with leisure), which have been shown to have significant effects on caregiver's outcomes in cross-sectional studies (e.g. Mausbach et al., in press), also predict changes in depression over time.

Regarding the use of the emotional regulation strategy cognitive reappraisal, this is, the ability to cognitively construct a potentially negative emotion-eliciting situation in a way that changes its emotional impact, this study showed a negative association between this variable and caregiver's depression over time. These results were consistent with a previous cross-sectional study (Romero-Moreno et al., in press), in which it was found that a higher use of cognitive reappraisal strategy was associated with lower levels of caregiver's distress (depression, anxiety and anger). Specifically, the results showed that increases in cognitive reappraisal over time predicted decreases in depression over time. This result was similar to that reported by Márquez-González, Losada, Peñacoba and Romero-Moreno (2009), who found that optimism was a significant inverse predictor of dementia caregivers' depression, even after controlling for caregivers' stressors.

So, the results of this study provide empirical support for the stress and coping model, showing that modulator variables contribute significantly to the explanation of their depressive symptoms. Specifically, changes in caregivers scores on the assessed modulator variables explain changes in their scores in depression in the way that is predicted by the model.

In addition, even though in a previous study (Losada et al., in press) a significant reduction in caregivers who participated in the intervention in depression scores was found when comparing baseline data with post-intervention scores, no significant effect for treatment condition was found in this study for the one year follow up. However, the results indicated a trend for caregivers in the intervention group to report lower levels of depression over time, when compared to caregivers in the control group.

Several limitations of this study must be acknowledged. Most of the sample consisted of volunteer caregivers recruited through Social and Day Care centers, and so it may not be possible to generalize these findings to all dementia caregivers. Also, although

the nature of this study is longitudinal, the results should not be taken as a demonstration of causality. Experimental studies are needed to appropriately address this issue. In addition, other potential variables that have not been considered in this study may also have an influence on caregiver's depression over time. For example, Schulz et al. (2008) found that increases in perceived dementia patient´s suffering were associated with increases in caregiver depression, even after controlling for objective stressors (e.g. frequency of behavioral problems). Other caregiving stressors such as limitations in care recipient´s functional capacity should be considered by future longitudinal research, although significant associations between changes in functional capacity and frequency of behavioral problems over time have been reported (e,g., Jefferson et al., 2006) and frequency of behavioral problems seems to be the stressor variable that most contributes to explain caregiver's distress (Holley and Mast, 2010).

In addition, it would be interesting to analyze longitudinally cultural differences in the relationship between modulating variables and caregiver' depression. as cultural differences in caregiver levels of depression over time –with more levels reported by White caregivers as compared to African American caregivers- have been found (Roth, Haley, Owen, Clay and Goode, 2001).

Although the obtained results show that significant changes in most of the assessed modulating variables predict changes in depression, they do not provide information regarding the mechanisms of action through which these variables influence caregiver's depression. It would be interesting to analyze the mechanisms by which the modulating variables, such as self-efficacy, cognitive reappraisal and behavioral activation have an effect on changes in caregiver' depression. It may be plausible that the extent to which caregivers see themselves as being able to control their negative thoughts -high levels of self-efficacy- lead them to use a more adaptive coping strategies (e.g.

engagement in leisure activities and use of cognitive reappraisal) which could have positive consequences on caregiver's depression. In this sense, Li, Seltzer and Greenberg (1999) carried out a longitudinal study and suggested that caregivers who felt more control over their lives (i.e. who had high levels of mastery) tended to use problem-focused strategies (e.g. positive reinterpretation), which led to decreases in depressive symptoms. Future longitudinal and experimental studies are needed which analyze the direction of the relationships between modulating variables and caregiver's depression.

The results of this study contribute to the literature on dementia caregiving, providing longitudinal support to the stress and coping model in order to understand caregivers distress. Also, this study highlighted the importance of considering specific caregivers modulating or resources variables to predict caregiver's depression over time. Specifically, the results suggest that the modulating variables self-efficacy for controlling upsetting thoughts, behavioral activation and cognitive reappraisal have a positive impact on caregiver's symptoms of depression over time, even after controlling for caregiver's frequency of behavioral problems.

These results could have relevant clinical implications for the design and development of caregiver's interventions, as these modulating variables may be modified through teaching and training different skills, such us cognitive restructuring or/ and increasing behavioral activation (Losada et al., in press). Moreover, it is likely that training caregivers in these abilities may also impact care-recipients, by reducing the frequency of caregiver's abusive behaviours toward them or the desire to institutionalize them, provided that caregiver's depression over time have shown to predict these variables (Cooper et al., 2010; Arai et al., 2001).

8.7 References

Arai, Y., Sugiura, M., Washio, M., Miura, H., & Kudo (2001). Caregiver depresión predicts early discontinuation of care for disabled elderly at home. *Psychiatry and Clinical Neurosciences 55,* 379-382.

Arai, Y., Zarit, S.H., Sugiura, M., & Washio, M. (2002). Patterns of outcome of caregiving for the impaired elderly: a longitudinal study in rural Japan. *Aging & Mental Health, 6,* 39–46

Ballard, C.G, Eastwood, C., Gahir, M., and Wilcock, G.K. (1996). A follow-up of depression in the carers of dementia sufferers. *British Medical Journal,* 312:947.

Beach, S.R., Schulz, R., Yee, J.L., & Jackson, S. (2000). Negative and health effects of caring for a disabled spouse: longitudinal findings from the caregiver health effects study. *Psychology and Aging, 15,* 259-271.

Berger, G., Bernhardt, T., Weimer, E., Peters, J., Kratzsch, T., & Frolich, L., (2005). Longitudinal Study on the Relationship Between Symptomatology of Dementia and Levels of Subjective Burden and Depression Among Family Caregivers in Memory Clinic Patients. *Journal of Geriatric Psychiatry and Neurology, 18, 119-128.*

Black, W. and Almeida, O.P. (2004). A systematic review of the association between the Behavioral and Psychological Symptoms of Dementia and burden of care. *International Psychogeriatrics, 16,* 295-315.

Clay,O.J., Roth, D.L., Wadley, V.G., and Haley, W.E. (2008). Changes in social support and their impact on psychosocial outcome over a 5-year period for African American and White dementia caregivers. *International Journal of Geriatric Psychiatry, 23,* 857-862.

Coehlo, D.P., Hooker, K., & Bowman, S. (2007). Institutional placement of persons with dementia: what predicts occurrence and timing? *Journal of Family Nursing, 13,* 253-277.

Cooper, C., Blanchard, M., Selwood, A., Walker, Z., and Livingston, G. (2010). Family carers' distress and abusive behaviour: longitudinal study. *The British Journal of Psychiatry: The Journal of Mental Sciences, 196,* 480-485.

Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International*

Journal of Geriatric Psychiatry, 23, 929-936.

Cuijpers, P. (2005).Depressive disorders in caregivers of dementia patients. *Aging & Mental Health, 9,* 325–330

Danhauer, S.C., McCann, J.J., Gilley, D.W., Beckett, L.A., Bienias, J.L., Evans, D. A. (2004). Do behavioral disturbances in persons with Alzheimer's Disease predict caregiver depression over time. *Psychology and Aging,19, 198-202.*

Ducharme, F., Lévesque, L., Zarit, S.H., Lachance, L., & Giroux, F. (2007). Changes in health outcomes among older husband caregivers: a one-year longitudinal study. *The International Journal of Aging and Human Development, 65,* 73-96.

Epstein-Lubow, G., Davis, J.D., Miller, I.W.,& Tremont, G. (2008). Persisting burden predicts depressive symtoms in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology, 21,* 198-203.

Gaugler, J.E. (2010). The longitudinal ramifications of stroke caregiving: A systematic review. *Rehabilitation Psychology, 55,* 108-125.

Gaugler, J.E., Kane, R.L., Kane, R.A., & Newcomer, R. (2005). The longitudinal effects of early behavior problems in the dementia caregiving career. *Psychology and Aging, 20*, 100-116.

Gotlieb, B.H., & Rooney, J.A. (2004). Coping effectiveness: Determinants and relevance to the mental health and affect of family caregivers of persons with dementia. *Aging and Mental Health, 8*, 364-373.

Haley, W.E., Levine, E.G., Brown, L., & Bartolucci, A.A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging, 2,* 323-330.

Heru, A.M.,& Ryan, C.E. (2006). Family Functioning in the Caregivers of Patients with Dementia: One-Year Follow-up. *Bulletin of the Menninger Clinic, 70, 222-231.*

Holley, C.K., and Mast, B.T. (2010). Predictors of anticipatory grief in dementia caregivers. *Clinical Gerontologist: The Journal of Aging and Mental Health, .33*, 223-236.

Jefferson, A. L., Cahn-Weiner, D., Boyle, P., Paul, R.H., Moser, D.J., Gordon, N. C., Ronald A. (2006). Cognitive predictors of functional decline in vascular dementia. *International Journal of Geriatric Psychiatry, 21, 752-754.*

Joling, K.J., van Hout, H.P.J; Schellevis, F. G. van der, H., Henriette, E., Scheltens, P. Knol, D.L.,& van Marwijk, H.W. J.(2010). Incidence of depression and anxiety in

the spouses of patients with dementia: A naturalistic cohor study of recorded morbidity with a 6-year follow-up. *The American Journal of Geriatric Psychiatry,18,146-153.*

Knussen, C. Tolson, D., Brogan, C. A., Swan, I.R.C, Stott, D.J., Sullivan, F. (2008). Family caregivers of older relatives: Ways of coping and change in distress. *Psychology, Health & Medicine, 13,* 274-290.

Kraemer, H.C. and Blasey, C.M. (2004). Centring in regression analyses: a strategy to prevent errors in statistical inference. *International Journal of Methods in Psychiatric Research, 13,* 141-151.

Li, L.W., Seltzer, M.M., & Greenberg, J.S. (1999). Change in depressive symptoms among daughter caregivers: An 18-month longitudinal study. *Psychology and Aging, 14,* 206-219.

Losada, A., Márquez-González, M., and Romero-Moreno, R. (in press). Mechanisms of action of a psychological intervention for dementia caregivers: effects of behavioural activation and modification of dysfunctional thoughts. *International Journal of Geriatric Psychiatry*.

Losada, A., Pérez-Peñaranda, A., Rodríguez, E., Gómez, M.A., Ballesteros, C., Ramos, I., Campo, M.A. & García, L. (2010). Leisure and distress in caregivers for elderly patients. *Archives of Gerontology and Geriatrics, 50*, 347-350.

Lyons, K.S., Steward, B.J., Archbold, R.N., & Carter, J.H. (2009). Optimism, Pessimism, Mutuality, and Gender: Predicting 10-Year Strain in Parkinson's Disease Spouses. *The Gerontologist, 49,* 378-387.

Márquez-González, M., Losada, A., López, J., & Peñacoba, C. (2009). Reliability and validity of the Spanish version of the revised scale for caregiving self-efficacy. *Clinical Gerontologist, 32,* 1–11.

Márquez-González, M., Losada, A., Peñacoba, C. y Romero-Moreno, R. (2009). El optimismo como factor moderador de la relación entre el estrés y la depresión de los cuidadores informales de personas mayores dependientes. *Revista Española de Geriatría y Gerontología, 44,* 251-255.

Mausbach, B., Patterson, T., Rabinowitz, Y., Grant, I., Schulz, R. (2007) .Depression and distress predict time to cardiovascular disease in dementia caregivers. *Health Psychology 26*, 539–544.

Mausbach, B., Patterson, T., Rabinowitz, Y., von Känel, R., Mills, P.J., Dimsdale, J.E.,

Ancoli-Israel, S., & Grant, I. (2007). The attenuating effect of personal mastery on the relations between stress and Alzheimer caregiver health: A five-year longitudinal analysis. *Aging and Mental Health, 11,* 637-644.

Mausbach, B.T., Roepke, S.K., Depp, C.A., Moore, R., Patterson, T.L., & Grant, I. (in press). Integration of the Pleasant Events (PE) and Activity Restriction (AR) Models: Development and Validation of a "PEAR" Model of Negative Outcomes in Alzheimer´s Caregivers. *Behavior Therapy.*

Mausbach, B.T., Roepke, S.K., Depp, C.D., Patterson, T.L., & Grant, I. (2009). Specificity of cognitive and behavioral variables to positive and negative affect. *Behaviour Research and Therapy, 47,* 608-615.

O'Rourke, N., & Tuokko, H.A. (2004). Caregiver burden and depressive symptomatology: The association between constructs over time. *Clinical Gerontologist: The Journal of Aging and Mental Health, 27, 41-52.*

O'Rourke, N., Cappeliez, P.,& Neufeld, E. (2008). Recurrent depressive symtomatology and physical health: A 10-year study of informal caregivers of persons with dementia. *The Canadian Journal of Psychiatry, 52, 434-441.*

Perren, S., Schmid, R., & Wettstein, A. (2006). Caregivers' adaptation to change: The impact of increasing impairment of persons suffering from dementia on their caregivers' subjective well-being. *Aging & Mental Health,10,* 539–548

Pinquart, M., & Sörensen, S. (2003). Differences between Carevigers and noncarevigers in psychological health and physical health: a meta-analysis. *Psychology and Aging 18,* 250-267.

Radloff, L.S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1,* 385-401.

Romero-Moreno, R., Márquez-González, M., Losada, A., & López, J. (in press). Motives for caring: relationship to stress and coping dimensions. *International Psychogeriatrics.*

Romero-Moreno, R., Mausbach, B.T., Losada, A., Márquez-González, M., Patterson, T.L., & López, J. (in press). Analysis of the moderating effect of self-efficacy domains in different points of the dementia caregiving process. *Aging and Mental Health.*

Roth, D.L., Haley, W.E., Owen, J.E., Clay, O.J., and Goode, K.T. (2001). Latent growth models of the longitudinal effects of dementia caregiving: a comparison of African

American and White family caregivers. *Psychology and Aging, 16,* 427-436.

Salovey, P., Mayer, J.D., Goldman, S.L., Turvey, C. and Palfai, T.P. (1995). Emotional attention, clarity, and repair: Exploring emotional intelligence using the Trait Meta-Mood Scale. In J.W. Pennebaker, (Eds). *Emotion, Disclosure, and Health* (pp.125-154). Washington, D.C.: American Psychological Assn.

Schulz, R., and Williamson, G.M. (1991). A 2-year longitudinal study of depression among Alzheimer's caregivers. *Psychology and Aging, 6,* 569-578.

Schulz, R., McGinnis, K.A, Zhang, S., Martire, L.M.,Hebert, R.S., Beach, S.R., Zdaniuk, B., Czaja, S.J.,& Belle, S.H. (2008). Dementia patient suffering and caregiver depression. *Alzheimer Disease and Associated Disorders, 2,* 170-176.

Schulz, R., O´Brien, A.T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist, 35*, 771-791.

Searson, R., Hendry, A. M, Ramachandran, R., Burns, A., & Purandare, N. (2008). Activities enjoyed by patients with dementia together with their spouses and psychological morbidity in carers. *Aging & Mental Health,12,* 276-282.

Shaw, W.S., Patterson, T.L., Semple, S.J., Ho, S., Irwin, M.R., Haugler, R.L., & Grant, I. (1997). Longitudinal analysis of multiple indicators of health decline among spousal caregivers. *Annals of Behavioral Medicine, 19,* 101-109.

Steffen, A.M., McKibbin, C., Zeiss, A.M., Gallagher-Thompson, D., & Bandura, A. (2002). The revised scale for caregiving self-efficacy: Reliability and validity studies. *Journal of Gerontology: Psychological Sciences, 57,* 74–86.

Stevens, A.B., Coon, D., Wisniewski, S., Vance, D., Arguelles, S., Belle, S., Mendelsohn, A., Ory, M. y Haley, W. (2004). Measurement of leisure time satisfaction in family caregivers. *Aging and Mental Health, 8*, 450-459.

Taylor, D.H., Ezell, M., Kuchibhatla, M., Østbye, T., & Clipp, E.C. (2008). Identifying Trajectories of Depressive Symptoms for Women Caring for Their Husbands with Dementia. *Journal of the American Geriatrics Society, 56,* 322-327.

Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P.P. (1992). Assessment of Behavioral Problems in Dementia: The Revised Memory and Behavior Problems Checklist. *Psychology and Aging, 7,* 622-631.

Vitaliano, P.P., Young, H.M., & Zhang, J. (2004). Is caregiving a risk factor for illness? *Current Directions in Psychological Science, 13*, 13-16.

Wassertheil-Smoller, S., Applegate, W.B., Berge, K., Chang, C.J., Davis, B.R., Grimm, R.J., Kostis, J., Pressel, S., Schron, E., 1996. Change in depression as a precursor of cardiovascular events. SHEP Cooperative Research Group (Systoloc Hypertension in the elderly). *Archives of Internal Medicine,156*, 553–561.

Wright, L.K. (1994). AD spousal caregivers. Longitudinal changes in health, depression, and coping. *Journal of Gerontological Nursing, 20,* 33-48.

9. Discusión general

En este apartado se comentan los principales resultados de los estudios realizados y se exponen las principales conclusiones extraídas de esta tesis doctoral. En primer lugar, se analiza en qué medida las características de la muestra de estos estudios son similares a las obtenidas en otros estudios previos con población cuidadora y permiten, por tanto, comparar los resultados obtenidos en estos estudios con los encontrados por estudios previos. En segundo lugar, se revisa la consecución de los objetivos planteados en los estudios, comentando las principales aportaciones y conclusiones de cada uno de ellos. Además se realiza una reflexión sobre la aportación conjunta de los estudios al estudio del cuidado. Posteriormente, se comentan cuáles son las implicaciones prácticas de los estudios, así como las posibles líneas de investigación futura. Finalmente, se presentan las limitaciones de este trabajo.

9.1 Características sociodemográficas de la muestra

En general, los datos descriptivos obtenidos tanto en los estudios transversales de este trabajo (Estudios 1, 2 y 3) como en el estudio longitudinal (Estudio 4) muestran que el perfil de la muestra de los cuidadores familiares de personas con demencia participantes en este trabajo de tesis es similar al encontrado en otros estudios, tanto nacionales como internacionales. Así, las características de los participantes de este trabajo no difieren sustancialmente de las encontradas en un estudio representativo realizado en nuestro país por el IMSERSO (2005). Los porcentajes de mujeres que han participado el presente trabajo, que oscilan entre un 77.20% en el Estudio 1 y un 81.10% en el Estudio 4, no difieren significativamente del 83.6% de mujeres cuidadoras encontrado en el estudio del IMSERSO (2005). De la misma manera, otras características de la muestra de los cuatro estudios que componen este trabajo (p.ej., parentesco con la persona cuidada, edad media

del cuidador, horas diarias de dedicadas al cuidado, etc.), son similares al perfil característico nacional (IMSERSO, 2005). Finalmente, las puntuaciones medias obtenidas en las escalas que han sido utilizadas en otros estudios relevantes de carácter internacional (p.ej., las escalas CES-D, RMBPC, ZBI, RSCSE, CJCS y LTS; Burgio y otros, 2003; Dilworth-Anderson y otros, 1999; Shaw y otros, 2003; Mittelman y otros, 2004; Schulz y otros, 1995; Stevens otros, 2004; Steffen y otros, 2002; Zarit y otros, 1980), sugieren que la muestra de este trabajo se puede comparar a otras muestras de cuidadores, si bien hay que señalar que, como se indicará más adelante al comentar sus limitaciones, se trata de una muestra de conveniencia. Por tanto los resultados obtenidos en el presente trabajo se podrían comparar con los resultados obtenidos en otros estudios al tratarse de muestras con características similares.

9.2 Resumen de las principales aportaciones de los estudios

Desde finales de los 80 se han realizado adaptaciones del modelo de estrés y afrontamiento de Lazarus y Folkman (1984) al cuidado familiar de personas con demencia (p.ej., Haley y otros, 1987; Díaz-Veiga, Montorio y Yanguas, 1999; Pearlin y otros, 1990). Si bien desde entonces, tal y como se ha señalado en otros puntos de esta Tesis doctoral, este modelo ha guiado gran parte de la investigación en el cuidado, no ha sido hasta recientemente que se han propuesto adaptaciones de este modelo que consideren la composición multidimensional de las variables hasta ahora estudiadas en el cuidado, como por ejemplo la cultura (p.ej., Aranda y Knight, 1997). Es más, todavía más reciente es la revisión del modelo sociocultural de estrés y afrontamiento en la que se sugiere que las variables culturales afectan al malestar del cuidador a través de su efecto sobre las estrategias de afrontamiento y el apoyo social, y no a través de su efecto sobre la carga del cuidador (Knight y Sayegh, 2010). De la misma forma, en la mayor parte de los trabajos

basados en este modelo se asume que las variables moduladoras ejercen su función interviniendo entre los estresores a los que se enfrentan los cuidadores y el malestar y las consecuencias del cuidado. Hasta donde sabemos, no se han realizado estudios que analicen la posible influencia de diferentes variables moduladoras en diferentes momentos del proceso de estrés, y no se han realizado estudios longitudinales sobre el malestar del cuidador basados en el modelo de estrés y afrontamiento.

El objetivo general de los estudios que componen esta Tesis Doctoral fue el de analizar, con metodología tanto transversal como longitudinal, el papel que tienen distintas variables moduladoras en el proceso de estrés del cuidado en familiares de personas con demencia. Concretamente, teniendo en cuenta el modelo teórico de estrés y afrontamiento adaptado al cuidado (ej., Haley y otros, 1987; Knight y Sayegh, 2010), se analizó: a) transversalmente, el papel de las variables moduladoras de autoeficacia percibida del cuidador, motivos culturales para cuidar y frecuencia y satisfacción con la activación conductual en el proceso de estrés del cuidador; y b) longitudinalmente, el papel de las variables moduladoras autoeficacia para controlar pensamientos negativos, frecuencia de activación conductual y reevaluación cognitiva en malestar del cuidador.

En primer lugar, se analizó el papel moderador de dos dimensiones de la autoeficacia en diferentes momentos del proceso de estrés del cuidador. Concretamente, por un lado (Estudio 1), se analizó si la autoeficacia para manejar comportamientos problemáticos moderaba la relación entre la frecuencia de comportamientos problemáticos y la carga del cuidador y, por el otro, si la autoeficacia para controlar pensamientos negativos moderaba la relación entre la carga del cuidador y sus niveles de malestar (depresión y ansiedad). En segundo lugar (Estudio 2), se analizó la relación entre los motivos para cuidar y distintas variables relativas al proceso de estrés. Específicamente, se analizaron las propiedades psicométricas de la Escala Justificaciones Culturales para el

Cuidado-Revisada y su relación con las estrategias de regulación emocional, rumiación y reevaluación cognitiva, y con el malestar del cuidador (depresión, ansiedad e ira). En tercer lugar (Estudio 3), se analizó el efecto de la consideración simultánea de la frecuencia y la satisfacción con la activación conductual sobre: a) las estrategias de regulación emocional de los cuidadores; b) su salud mental (depresión y ansiedad); c) su salud física percibida y; d) sobre el riesgo de institucionalización del cuidador. Finalmente (Estudio 4), se analizó si los cambios en las variables moduladoras, autoeficacia para controlar pensamientos negativos, frecuencia de activación conductual y reevaluación cognitiva, predecían las variaciones en depresión de los cuidadores a lo largo del tiempo (1 año), controlando el género y los estresores del cuidador.

A continuación, se exponen brevemente las principales aportaciones de cada uno de los estudios:

Estudio Uno

Los resultados obtenidos en el primer estudio sugieren que, en contra de lo hipotetizado, la autoficacia para manejar comportamientos problemáticos no modera la relación entre la frecuencia de comportamientos problemáticos y la carga del cuidador, sino que tiene un efecto positivo general, dado que amortigua los efectos de los comportamientos problemáticos tanto en niveles bajos como altos de esta variable sobre la carga. Por otro lado, de acuerdo con lo esperado, los resultados indican que la autoeficacia para controlar pensamientos negativos modera la relación entre la carga del cuidador y sus niveles de malestar (depresión y ansiedad). La aportación principal de este estudio es que aporta apoyo empírico a la hipótesis de que la autoeficacia –considerada de forma multidimensional- tiene un papel moderador en la relación entre carga y malestar del cuidador. Además, los resultados de este estudio subrayan algo que no ha sido

suficientemente atendido en la investigación: la importancia de analizar tanto las variables de resultado como los posibles procesos de mediación y moderación por parte de las variables moduladoras en distintos momentos del proceso de estrés.

Estudio Dos

Los resultados del segundo estudio contribuyen a respaldar la importancia de considerar variables de tipo cultural, tales como los motivos para cuidar, en la investigación en el área del cuidado, tan escasamente abordadas por los estudios hasta la fecha. Los resultados obtenidos indican que la Escala de Motivos Culturales para el Cuidado-Revisada presenta adecuadas propiedades psicométricas, tales como adecuados índices de consistencia interna y una adecuada validez factorial (de constructo), como puede apreciarse en el resultado relativo a que un porcentaje significativo de la varianza es explicada a partir de los dos factores obtenidos en el análisis factorial. Por otro lado, los distintos patrones de asociación que presentan estos dos factores con el resto de variables moduladoras y de resultado analizadas son evidencias que apoyan la validez de criterio de este instrumento.. Sin embargo, la estructura bifactorial encontrada para la escala en este estudio (motivos extrínsecos e intrínsecos para el cuidado) no es consistente con lo hipotetizado, de modo que los resultados encontrados no confirman la unidimensionalidad de dicha escala encontrada en estudios previos (Dilworth-Anderson, 2004).Otra de las principales aportaciones de este estudio es que aporta datos que subrayan la importancia de analizar los perfiles específicos de los cuidadores definidos por la combinación de las dos subdimensiones identificadas en los motivos culturales en el proceso de estrés del cuidador (motivos extrínsecos e intrínsecos). Así, las diferencias encontradas entre estos perfiles en las variables de regulación emocional y las consecuencias del cuidado demuestran la importancia de tener en cuenta de forma simultánea estas subdimensiones e

indican que la contemplación aislada de una de ellas sin tener en cuenta la otra nos haría perder información muy importante. Concretamente, en el estudio se ha identificado un perfil de cuidadores con mayor vulnerabilidad psicológica, a saber, el definido por puntuaciones altas en motivos extrínsecos y bajas en motivos intrínsecos. Estos cuidadores utilizan estrategias de regulación emocional más desadaptativas (mayores niveles de rumiación y menores de reevaluación cognitiva) y manifiestan mayor malestar psicológico (depresión, ansiedad e ira). Estos resultados demuestran la relevancia de los aspectos motivacionales en el cuidado familiar y aportan pistas importantes para la intervención, que serán comentados más adelante al abordar las implicaciones prácticas de los estudios.

Estudio Tres

Los datos encontrados en el tercer estudio señalan la importancia de prestar atención no sólo a la frecuencia de realización de actividades agradables, sino también y de forma simultánea, a la satisfacción de la persona con dichas actividades. Así, los resultados de este estudio subrayan la conveniencia de analizar de forma conjunta el efecto que tienen ambas variables (el perfil de ocio del cuidador) en el proceso de estrés del cuidado. Los resultados obtenidos apoyan empíricamente el modelo teórico "PEAR" (Pleasent Events Activity Restriction), propuesto por Mausbach y otros (2009), en la explicación del efecto del ocio en el proceso del cuidado. Nuevamente, la metodología aplicada permitió la identificación de cuatro perfiles de ocio (resultantes de la combinación de niveles altos y bajos en ambas variables) y la obtención de evidencia empírica que indica que los cuidadores con bajos niveles de frecuencia y satisfacción con la activación conductual utilizan estrategias de regulación emocional menos adaptativas (más rumiación y menos reevaluación) y presentan mayores niveles de malestar (ansiedad,

depresión, salud física percibida) que los cuidadores con cualquier otro perfil de ocio. Por el contrario, este estudio indica que aquellos cuidadores con altos niveles tanto de frecuencia como de satisfacción con la activación conductual muestran estrategias de regulación emocional más adaptativas (menor rumiación y mayor revaluación cognitiva), presentando menores niveles de malestar y de riesgo de institucionalizar a sus familiares (deseo de institucionalización).

Estudio Cuatro

Finalmente, los resultados del cuarto estudio contribuyen a respaldar la utilidad del modelo de estrés y afrontamiento en la investigación longitudinal sobre el cuidado. Los resultados obtenidos sugieren que la inclusión de variables moduladoras para explicar la depresión del cuidador a lo largo del tiempo aumenta de forma significativa el porcentaje de varianza explicada por otras variables consideradas habitualmente en la investigación sobre el cuidado (género y frecuencia de comportamientos problemáticos). Concretamente, los resultados indican que los aumentos en la autoeficacia para controlar pensamientos negativos, en el nivel de activación conductual y en el empleo de la estrategia de regulación emocional de reevaluación cognitiva, contribuyen a explicar significativamente los descensos en la depresión del cuidador a lo largo del tiempo (1 año), controlando el efecto del género y de los estresores (frecuencia de comportamientos problemáticos). El carácter longitudinal de la metodología empleada en este estudio ha permitido identificar que los cambios en las variables moduladoras analizadas covarían en el tiempo a los cambios en la depresión del cuidador, aportando de este modo pistas fundamentales sobre los mecanismos explicativos del malestar de los cuidadores y proporcionando respaldo empírico a las intervenciones dirigidas a fomentar la activación

conductual y la revaluación cognitiva (muy relacionada con la autoeficacia para controlar pensamientos negativos).

9.3 Conclusiones generales de los cuatro estudios.

9.3.1 Importancia de la multidimensionalidad de las variables moduladoras

Una de las aportaciones principales de este trabajo es que proporciona apoyo empírico que subraya la necesidad de considerar el carácter multidimensional devariables moduladoras autoeficacia percibida y motivos por los que se cuida, las cuales, hasta la fecha, se habían considerado de forma unidimensional. En este sentido, los resultados del Estudio 1 permiten identificar un papel moderador para uno de los factores de la autoeficacia, concretamente, la autoeficacia para controlar pensamientos negativos, que amortigua el impacto que la carga del cuidador tiene sobre sus niveles de depresión y ansiedad, pero no para otro de los factores de la autoeficacia, a saber, la autoeficacia para el manejo de comportamientos problemáticos. Sin embargo, se ha encontrado que, si bien la autoeficacia para manejar comportamientos no modera la relación entre estresores (frecuencia de comportamientos problemáticos) y carga del cuidador, esta dimensión parece tener un efecto positivo general, siendo adaptativa tanto para cuidadores que se enfrentan a niveles altos como bajos de comportamientos problemáticos.

Por su parte, los datos del estudio 2 sugieren que, en contra de lo encontrado por otras investigaciones previas (p.ej., Dilworth-Anderson y otros, 2004), la variable motivos culturales para cuidar, medida a través de la Escala Justificaciones Culturales para el Cuidado-Revisada, no tiene una estructura unidimensional, sino que se compone de dos factores que han sido denominados "motivos extrínsecos" y "motivos intrínsecos" para el cuidado. Asimismo, la validez de la estructura bidimensional de los motivos para cuidar se ve avalada por la identificación de distintos patrones de asociación entre estas

subdimensiones y las estrategias de regulación emocional empleadas por los cuidadores, así como sus niveles de malestar del cuidador.

9.3.2 La importancia de la identificación de perfiles de los cuidadores en las dimensiones de las variables moduladoras

El conjunto de estudios que componen esta Tesis Doctoral sugiere no sólo que es útil para explicar el malestar de los cuidadores analizar las variables moduladoras en sus dimensiones o factores, sino que, además, es importante analizar los efectos que tiene la combinación de dichas dimensiones entre sí en el proceso de estrés (p.ej., cuidadores con altas puntuaciones en motivos extrínsecos y bajas puntuaciones en motivos intrínsecos). En este sentido, el hecho de considerar distintos grupos de cuidadores en función de las combinaciones de puntuaciones altas y bajas en distintas dimensiones de una variable o ámbito (motivos extrínsecos e intrínsecos en el Estudio 2; y frecuencia y satisfacción con la activación conductual en el Estudio 3) permite identificar perfiles de cuidadores con mayor riesgo de manifestar malestar psicológico y físico, así como de utilizar, en mayor medida, estrategias de regulación emocional desadaptativas. La estrategia de análisis basada en la consideración aislada de las dimensiones ha sido la más habitualmente empleada en la investigación sobre el cuidado y, sin embargo, no permite el acceso a información muy útil que sólo puede obtenerse al analizar las combinaciones o perfiles en las diferentes dimensiones.

Concretamente, en este trabajo se han encontrado dos perfiles de cuidadores en riesgo: a) aquellos que cuidan sólo “por obligación” y no “porque quieren” , es decir, aquellos que tienen puntuaciones altas en motivos extrínsecos y bajas en motivos intrínsecos para cuidar (Estudio 2); y b) aquellos que ni “hacen” ni “disfrutan haciendo” actividades de ocio, es decir, los que tienen puntuaciones bajas tanto en frecuencia como

en satisfacción con la activación conductual o actividades agradables o de ocio (Estudio 3).

Los resultados de los Estudios 2 y 3 sugieren que ambos perfiles de cuidadores presentan mayores niveles de malestar psicológico que los cuidadores con otros perfiles y, en comparación con éstos, utilizan estrategias de regulación emocional más desadaptativas; mayor frecuencia de rumiación emocional y menor frecuencia de reevaluación cognitiva. En este punto es importante recordar que los datos obtenidos de los Estudios 2 y 3 muestran que los dos perfiles de cuidadores en riesgo identificados en estos trabajos no presentan mayores niveles de estresores objetivos que el resto de los grupos de cuidadores en los que se dividió la muestra. Igualmente, resulta interesante subrayar el peso más relevante que tienen las variables relacionadas con aspectos subjetivos del cuidador (p.ej., motivos para cuidar o perfil de ocio) en comparación con dimensiones más objetivas del cuidador (p.ej., capacidad funcional o frecuencia de comportamientos problemáticos) para explicar el malestar psicológico (p.ej., depresión, ansiedad).

Por tanto, identificar el perfil de los cuidadores que puntúan: a) alto en motivos extrínsecos y, a la vez, bajo en motivos intrínsecos; b) y/o, bajo tanto en frecuencia como en satisfacción con actividades agradables; puede resultar importante a la hora de planificar y diseñar intervenciones psicológicas dirigidas de forma específica a tratar el malestar psicológico de los cuidadores.

Del mismo modo, los resultados obtenidos en este trabajo permiten identificar diferentes perfiles de cuidadores que resultan ser más *adaptativos* o *protectores* durante el proceso de estrés del cuidado. En este sentido, los resultados del los Estudios 2 y 3 sugieren que, en general, los cuidadores que cuidan por motivos más internos o personales y no tanto por obligación, así como los que realizan más actividades agradables y, al

mismo tiempo, están más satisfechos con el tiempo que dedican a ello, utilizan estrategias de regulación emocional más beneficiosas (rumian menos y reevalúan más) y manifiestan menores niveles de malestar (depresión, ansiedad). De la misma manera, este último perfil, esto es, aquellos cuidadores con altos niveles tanto en frecuencia como en satisfacción con la activación conductual, informan de tener menos pensamientos relacionados con el deseo de institucionalizar a sus familiares.

El que estos cuidadores presenten perfiles asociados a menores niveles de malestar no debería entenderse en términos de que no necesitan ayuda (p.ej., intervenciones psicológicas). Tal y como señalan Zarit y Femia (2008) las intervenciones con cuidadores, para que sean eficaces, han de dirigirse a sus necesidades concretas. Los cuidadores con perfiles adaptativos podrían beneficiarse de intervenciones de promoción de hábitos o comportamientos saludables o de intervenciones formales que, a modo preventivo, facilitasen el mantenimiento de su situación actual.

9.3.3 Análisis del efecto modulador de variables psicológicas a lo largo del proceso de estrés

Igualmente, este trabajo contribuye a la investigación sobre el cuidado al subrayar la importancia de considerar el impacto que distintas dimensiones de la autoeficacia percibida tiene en distintos puntos del proceso del estrés (Estudio 1). Los resultados de este estudio sugieren que es importante tener en cuenta el punto del proceso de estrés en el que el cuidador se encuentra, que puede estar influido, entre otros factores, por el nivel de gravedad o por la fase de la enfermedad de la persona cuidada. Esta variable puede ser relevante a la hora de diseñar intervenciones psicológicas, dado que se ha comprobado que influye en los niveles de malestar del cuidador (Ferrara y otros, 2008).

Si bien es cierto que distintos estudios han puesto de manifiesto la importancia de considerar las necesidades específicas de los cuidadores a la hora de diseñar y planificar intervenciones psicológicas con ellos, teniendo en cuenta por ejemplo que existen necesidades diferentes entre esposos e hijos o hijas (p.ej., Cho, Zarit y Chiriboga, 2009), o entre hombres y mujeres (p.ej., Pinquart y Sörensen, 2006), este estudio contribuye a dar un paso más en este sentido. Considerar la combinación de distintas subdimensiones de un mismo constructo o variable (ej. motivos extrínsecos e intrínsecos o perfil de ocio) en el proceso de estrés permite identificar un perfil más específico de cuidador en riesgo de presentar malestar emocional, aspecto que cobra especial relevancia a la hora de diseñar y planificar intervenciones psicológicas. De esta manera, parece razonable pensar que cuanto más específico sea el perfil de cuidadores en riesgo, más probable es que se beneficie de una intervención hecha *a medida* para ese perfil concreto. Así, por ejemplo, mientras que existen estudios que resaltan que ser mujer es un factor de riesgo (Luztky y Knight, 1994) o que los cuidadores esposos tienen unas necesidades diferentes que los hijos e hijas (Peeters, Van Beek, Meerveld, Spreeuwenberg y Francke, 2010), lo cierto es que resulta difícil diseñar una intervención de la que se beneficien la mayoría de los esposos o hijas, ya que dentro de un mismo perfil pueden existir muchas diferencias entre ellos. En este sentido, tal y como se comentará más adelante, este estudio aporta datos interesantes con respecto al diseño, planificación e implementación de intervenciones con cuidadores de personas con demencia.

9.3.4 La importancia de la regulación emocional en el proceso de estrés

Los resultados tanto de los estudios transversales (Estudio 2 y 3), como del longitudinal (Estudio 4) sugieren que la inclusión de variables de regulación emocional en el modelo teórico de estrés y afrontamiento (Haley y otros, 1987; Knight y Sayegh, 2010),

hasta ahora no incluidas de forma explícita, contribuye de forma significativa a mejorar la explicación del malestar del cuidador. En este sentido, los resultados obtenidos en este trabajo sugieren que mayores niveles de rumiación emocional (estrategia ineficaz) y menores niveles de reevaluación cognitiva (estrategia eficaz) se asocian con mayores niveles de malestar (depresión y ansiedad) y con estrategias de afrontamiento más disfuncionales (p.ej., menos activación conductual) en los cuidadores. Si bien es cierto que existen estudios con población no cuidadora que muestran los efectos negativos de la estrategia de rumiación (Nolen-Hoeksema y otros, 2008) y los efectos positivos de la reevaluación cognitiva sobre la salud psicológica (Carver, Scheier y Weintraub, 1989), la inclusión de estas variables en la investigación sobre el cuidado de estas variables ha sido escasa hasta la fecha.

9.4 Implicaciones prácticas

Las diferencias encontradas en la relación entre estas subdimensiones y otras variables relevantes para el cuidado (p.ej., depresión, ansiedad, rumiación) sugieren que la consideración de diferentes perfiles específicos de los cuidadores proporcionará información relevante de cara a la planificación y diseño de intervenciones para esta población. Así, Zarit, Femia, Kim y Whitlatch (2010) destacan la necesidad de evaluar y diseñar intervenciones psicológicas individualizadas, en función de las combinaciones específicas de factores de riesgo en los cuidadores.

En este sentido, a la hora de intervenir con cuidadores tanto de forma grupal como individual, podría ser conveniente identificar si pertenecen a alguno de los perfiles en riesgo que se han identificado en este trabajo, y, en función del perfil encontrado, llevar a cabo el diseño y planificación de un tipo de intervención concreta.

Por ejemplo, a la hora de intervenir con cuidadores que cuidan sólo "por obligación", y no por motivos "personales", sería recomendable tratar de reducir los motivos extrínsecos y aumentar los intrínsecos para disminuir su malestar. En este sentido, es probable que los pensamientos o creencias disfuncionales relacionados con el cuidado (p.ej. Perfeccionismo o sentido de la responsabilidad; Montorio, Losada, Izal y Márquez-González, 2009) contribuyan a explicar los mayores niveles de malestar encontrados en este perfil de cuidadores (el que cuida por motivos extrínsecos y no por motivos intrínsecos). Potenciar desde la intervención terapéutica la modificación de pensamientos disfuncionales del cuidador por otros más adaptativos o realistas, mediante técnicas como la restructuración cognitiva (Burgio y otros, 2003; Gallagher-Thompson y otros, 2003; Márquez-González, Losada, Izal, Pérez-Rojo y Montorio, 2007) podría ser una herramienta para reducir los motivos extrínsecos. En este sentido a pesar de que, desde la terapia cognitivo-conductual, habitualmente no se haya abordado de forma explícita el trabajo en valores personales, es posible que, reduciendo los motivos extrínsecos del cuidador, éste se cuestione por qué continúa con su rol de cuidador, lo que favorecería a su vez el aumento de los motivos intrínsecos. Asimismo, una aproximación terapéutica potencialmente eficaz para este objetivo podría ser la Terapia de Aceptación y Compromiso (ACT; Hayes y otros, 1999). Desde esta terapia, se enfatizan dos aspectos fundamentales: la aceptación de eventos internos negativos (emociones, pensamientos, sensaciones corporales) y el compromiso con los valores personales de la persona a través del desarrollo de acciones comprometidas con tales valores. En este sentido, distintas herramientas terapéuticas empleadas desde este aproximación (Hayes y otros, 1999) (ej., clarificación de valores, propuesta y planificación de acciones comprometidas con los valores, aceptación de emociones y pensamientos negativos podrían ser beneficiosas para

este perfil de cuidadores que cuidan por "obligación" y no porque "quieren" (Márquez-González, Romero-Moreno y Losada, en prensa).

Centrando la atención en otro tipo de perfil, concretamente, en los cuidadores que realizan pocas actividades agradables y, al mismo tiempo, están poco satisfechos con el tiempo que emplean en realizarlas, parecería conveniente diseñar intervenciones psicológicas que fomenten el aumento de activación conductual de los cuidadores y, especialmente, su satisfacción con la activación conductual. En este sentido, aunque la literatura del cuidado muestra los beneficios terapéuticos para los cuidadores de intervenciones psicosociales dirigidas a potenciar la activación conductual (Gallagher-Thompson y otros, 2000; Losada y otros, en prensa), los resultados de este estudio sugieren que sería aconsejable hacer más hincapié en tratar de aumentar, igualmente, sus niveles de satisfacción con dicha activación conductual. Este aspecto cobra especial relevancia desde el punto de vista clínico o terapéutico ya que, aunque en general, las intervenciones dirigidas a aumentar la frecuencia de actividades agradables logren también aumentar su satisfacción con ellas (p.ej., Burgio, Stevens, Guy, Roth y Haley, 2003), existen estudios en los que los niveles de satisfacción con la activación conductual no han sido evaluados, o bien no se ha logrado aumentarlos (Backman y Mannell, 1986). En este sentido, las herramientas y técnicas clínicas que habitualmente se emplean para aumentar la activación conductual (p. ej., registro del estado de ánimo y de la frecuencia de actividades agradables realizadas, análisis de gráficos sobre su relación, análisis de posibles obstáculos para su realización, establecimiento de metas realistas, etc.; Gallagher-Thompson y otros, 2000; Thompson, Gallagher y Lovett, 1992) pueden resultar insuficientes para aumentar los niveles de satisfacción con las actividades agradables. La satisfacción con la activación conductual, independientemente de los niveles de frecuencia de la activación conductual, puede potenciarse desde la intervención terapéutica, a través

de la activación de los valores y preferencias personales de los cuidadores. En este sentido, la Terapia de Aceptación y Compromiso (Hayes y otros, 2009) vuelve a aparecer como una vía terapéutica prometedora, ya que ofrece herramientas para trabajar directamente con los valores de las personas. Es importante señalar que el trabajo centrado en los valores personales desde la intervención terapéutica ha recibido apoyo empírico en población no cuidadora, tales como personas con dolor crónico (Branstetter-Rost, Cushing y Douleh, 2009), padres de niños con trastornos del desarrollo (Blackledge y Hayes, 2006) o personas con diabetes (Gregg, Callaghan, Hayes y Glenn-Lawson, 2007), entre otras.

Por su parte, los resultados obtenidos del Estudio 1 sugieren que la autoeficacia para manejar comportamientos problemáticos es una variable que tiene efectos positivos generales, actuando como protectora para los cuidadores que tienen tanto altos como bajos niveles de frecuencia de estresores (comportamientos problemáticos). Por tanto, enseñar y entrenar a los cuidadores en técnicas para manejar los comportamientos problemáticos, lo cual viene siendo el objetivo de muchas intervenciones eficaces realizadas hasta la fecha (p., ej. técnicas de modificación de antecedentes y consecuentes; Martín-Carrasco y otros, 2009; Teri y otros, 2005), parece ser beneficioso para todos los cuidadores. Por otro lado, los resultados del Estudio 1 sugieren que los cuidadores que tengan niveles altos de carga se beneficiarán en mayor medida de intervenciones en las que se entrenen y potencien habilidades para aumentar la autoeficacia para controlar pensamientos negativos. En este sentido, técnicas de intervención como la reestructuración cognitiva, el aumento de la activación conductual (Rabinowitz y otros, 2006), la aceptación de pensamientos (Oken y otros, 2010) o la relajación (Fisher y Laschinger, 2001), pueden resultar útiles para dicho propósito.

Considerando los resultados de los estudios de forma conjunta, parece destacar un aspecto fundamental que sería recomendable tener en cuenta en el estudio del proceso del cuidado y que, sin embargo, ha recibido muy poca atención en la literatura del cuidado: los valores personales de los cuidadores. En este sentido, los valores, los objetivos y las metas de las personas han cobrado una especial relevancia en la investigación clínica con población no cuidadora, incrementándose su popularidad en los últimos años gracias a las perspectivas terapéuticas contextualistas, especialmente por la Terapia de Aceptación y Compromiso (p.ej., Hayes, Strosahl y Wilson, 1999). Concretamente, las llamadas terapias de tercera generación conceden una importancia central a los valores y objetivos de las personas, a los que consideran el marco que da sentido y dirige cualquier intervención psicológica. Rescatar, desde un enfoque humanista, el estudio de los valores personales es especialmente importante en la población cuidadora, ya que este colectivo está expuesto a una alto nivel de demandas físicas y psicológicas, lo que hace más probable que se desorienten y olviden cuál eran las metas y valores que daban sentido a sus vidas. Desde estas perspectivas, los valores personales marcan el contexto en la intervención, el marco desde el que se recomienda aplicar el resto de componentes terapéuticos.

De acuerdo con lo que sugieren Zarit y otros (2010), es razonable pensar que no todas las personas se beneficiarán de la misma manera de un tipo concreto de intervención, sino que es necesario abordar las intervenciones con cuidadores atendiendo a sus perfiles específicos de riesgo. Así, siguiendo a estos autores, los resultados de este trabajo sugieren que, de cara a mejorar las intervenciones terapéuticas con cuidadores, es importante: a) evaluar e identificar las variables fundamentales (con mayor poder predictivo) que definen los perfiles de riesgo (p.ej., motivos para cuidar y de activación conductual); b) determinar necesidades individuales de los cuidadores basadas en esta

evaluación; y, c) proporcionar tratamientos multicomponentes que respondan a las necesidades determinadas.

9.5 Futuras líneas de investigación

Si bien es cierto que los datos de la tesis avalan el importante peso que tienen las variables moduladoras en el proceso de estrés del cuidado y, especialmente, para explicar el malestar del cuidador, se necesitan futuros estudios que analicen cuáles son los mecanismos causales a través de los que estas variables moduladoras tienen su efecto en la salud psicológica de los cuidadores. Sería interesante analizar en qué sentido se relacionan la autoeficacia percibida del cuidador, las estrategias de regulación emocional que emplean los cuidadores y sus niveles de activación conductual para explicar sus niveles de depresión y ansiedad. Por un lado, podría ser posible que la percepción de control sobre el entorno de las personas (p. ej., altos niveles de autoeficacia percibida) influya en el desarrollo de estrategias de afrontamiento adaptativas, las cuales repercutan en el malestar del cuidador. Por otro lado, puede que como fruto del aprendizaje de estrategias de regulación adaptativas y de un mayor nivel de activación conductual, las personas lleguen a desarrollar reglas verbales positivas (p.ej., "soy capaz de afrontar la situación del cuidado") que influyen, a su vez, sobre las consecuencias del cuidador. Estas hipótesis han de ser exploradas por futuros estudios longitudinales y experimentales, ya que los resultados de este trabajo no permiten clarificar la dirección causal ni descartar una posible bidireccionalidad. En esta línea sería conveniente desarrollar estudios experimentales de intervención que nos permitieran comprobar si el entrenamiento a los cuidadores en el cambio de determinadas variables moduladoras (p.ej., regulación emocional o activación conductual) produciría cambios en las consecuencias del cuidado. Además, de esta manera, se podría observar si el entrenamiento en unas variables

moduladoras concretas (p.ej., regulación emocional) produciría cambios en otras variables moduladoras (p.ej., activación conductual), lo que nos permitiría profundizar en las hipótesis planteadas.

Igualmente, si bien en los diferentes estudios que componen la tesis se ha considerado el género como una variable de control, y no como un objetivo específico de los mismos, los datos del Estudio 4 sugieren que, en consonancia con lo encontrado en estudios previos, existe una mayor tendencia en las mujeres cuidadoras a manifestar mayor sintomatología depresiva a lo largo del tiempo (Schulz y Williamson, 1991), en comparación con los hombres. Igualmente, los datos obtenidos del Estudio 3 revelan que es más probable que el perfil de ocio que se considera más saludable, esto es, altos niveles de realización de actividades y satisfacción con ellas, esté formado por hombres cuidadores. Debido a que el género es una variable destacada en la literatura del cuidado, ya que la mayoría de los cuidadores son mujeres (83.6%, IMSERSO, 2005), sería interesante que futuros estudios analizasen en qué medida estas diferencias de género encontradas en el malestar emocional de los cuidadores están influidas por distintas variables moduladoras, como los motivos culturales para cuidar, las estrategias de regulación emocional empleadas o sus niveles de autoeficacia. Asimismo, sería interesante analizar en mayor medida las diferencias de los distintos patrones de asociación entre estas variables moduladoras y el malestar del cuidador en función del género.

Por otro lado, puesto que uno de los objetivos más deseados de las familias es el de "envejecer en casa", en la investigación del cuidado está cobrando especial importancia el análisis del riesgo de institucionalización de la persona cuidada. En este sentido, estudios previos muestran que los estresores (incapacidad functional y cognitive) (Habermann, Stephanie; Cooper, Claudia; Katona, Cornelius; Livingston, Gill, 2009), y la depresión de

los cuidadores (Cohen-Manstfield and Wirtz, 2009), influyen significativamente en el deseo de los cuidadores de institucionalizar a sus familiares, y por tanto, posiblemente, en su ingreso real. Los resultados obtenidos del Estudio 3 sugieren que la frecuencia y la satisfacción con las actividades agradables del cuidador pueden contribuir a la explicación del deseo de ingreso de los cuidadores, al haberse encontrado asociaciones negativas entre estas variables. Sin embargo, estos resultados hay que interpretarlos con cautela, ya que esta variable ha sido evaluada con un único ítem. Sería interesante, por lo tanto, analizar la influencia que las variables psicológicas del cuidador (p.ej., autoeficacia, regulación emocional) tienen sobre el riesgo de institucionalización.

Finalmente, en este estudio no se han analizado variables de salud física de los cuidadores, si bien se ha dado un primer paso en este sentido al encontrar, en el Estudio 3, que la frecuencia y la satisfacción con la activación conductual parecen tener efectos positivos sobre la salud percibida de los cuidadores. No obstante, estos resultados han de ser interpretados cuidadosamente, ya que esta variable (salud física percibida) ha sido evaluada de una manera general, a través de un único ítem, lo que puede estar afectando a la fiabilidad de los resultados. Sería interesante que futuros estudios analizasen el efecto de las variables moduladoras sobre distintas variables de salud física percibida, medidas a través de instrumentos de evaluación más específicos y fiables (p.ej., función física, rol físico, vitalidad y rol físico del Cuestionario de Salud SF-36; Alonso y otros, 1995), o mediante indicadores objetivos de salud física (p.ej., presión arterial o frecuencia cardiaca) (p.ej., Kim y Knight, 2008).

9.6 Limitaciones del estudio

Una de las limitaciones de este trabajo es que la muestra utilizada es de conveniencia, al tratarse de cuidadores familiares que han participado de forma voluntaria

en este estudio y que han sido reclutados a través de distintos centros de Servicios Sociales y Centros de Día de la Comunidad de Madrid. En este sentido, si bien es cierto que los datos descriptivos de la muestra son similares a los que habitualmente se encuentran en muestras de otros estudios, los resultados no se pueden generalizar a toda la población cuidadora. Se ha sugerido que el tipo de reclutamiento de la muestra influye en los resultados encontrados relacionados con el malestar de las personas mayores, habiéndose encontrado que las muestras no seleccionadas al azar presentan mayores índices de malestar (p.ej., preocupación) que las aleatorias (Izal, Nuevo, Montorio y Pérez- Rojo, 2009). Por otro lado, distintos estudios han encontrado que aquellas personas que utilizan recursos formales (p.ej., Servicios Sociales) poseen mejores estrategias de afrontamiento que los que no lo utilizan (Lamura y otros, 2008), por lo que sería interesante que futuras investigaciones analizasen los resultados de este estudio en aquellas personas que cuidan de sus familiares en sus hogares y no utilicen ningún tipo de servicio formal, a través por ejemplo, de estudios con selección aleatoria de la población.

Igualmente, si bien es cierto que este trabajo examina el papel que tienen distintas variables moduladoras en el proceso de estrés, tanto de forma transversal (Estudios 1, 2 y 3) como longitudinal (Estudio 4), los resultados obtenidos de él deben interpretarse con cautela, ya que no permiten establecer relaciones de naturaleza causal entre las variables analizadas. A pesar de que el modelo de estrés y afrontamiento adaptado al cuidado, en el cual se ha basado este trabajo, ha recibido importante respaldo empírico (Chun y otros, 2007; Haley y otros, 1997), pueden existir otras explicaciones posibles sobre la direccionalidad de las relaciones entre las variables. En este sentido, es posible que las consecuencias o variables dependientes de los cuidadores (p.ej., depresión) influyan sobre las variables moduladoras (ej. afrontamiento), lo que puede repercutir a su vez en la valoración que hacen los cuidadores de los estresores a los que se ven sometidos

(Schoenmakers y otros, 2009). Sin duda, se necesitan futuros estudios experimentales que permitan arrojar datos en este sentido.

Asimismo, los resultados relativos a los perfiles de riesgo de los cuidadores (Estudio 2 y 3) deben interpretarse con cautela debido al reducido tamaño muestral de algunos de los subgrupos en los que se ha dividido la muestra [p.ej., cuidadores que puntúan alto en motivos extrínsecos y bajo en motivos intrínsecos (n = 21) en el Estudio 2, o , aquellos que puntúan bajo en frecuencia con la activación conductual y alto en satisfacción con la activación conductual (n = 29) en el Estudio 3]. Sería interesante analizar estos resultados incrementando el tamaño muestral de estos subgrupos de cara a mejorar la generalización de los resultados. Igualmente, los resultados obtenidos al analizar las diferencias de género en el malestar del cuidador a lo largo del tiempo (ver Estudio 4) han de ser interpretarlos con cautela, ya que existe mucha menos proporción de hombres cuidadores que de mujeres cuidadoras, si bien es la proporción habitualmente reflejada en los estudios realizados con población cuidadora (ej., IMSERSO, 2005). Por otro lado, la pérdida muestral relativa al estudio longitudinal (Estudio 4) en los distintos momentos en los que se han evaluado a los cuidadores puede estar influyendo en los resultados obtenidos en dicho estudio, por lo que es necesario interpretarlos con precaución. Sin embargo, la proporción de datos perdidos en este estudio (Estudio 4), es similar a la obtenida por otros estudios longitudinales de cuidadores familiares (p.ej., Cooper y otros, 2008; Mausbach y otros, 2007).

Asimismo, existen algunas limitaciones relacionadas con los instrumentos de medida empleados en los diferentes estudios:

En primer lugar, se ha considerado la carga del cuidador como un único constructo –puntuación general de la escala-, (ver Estudio 1) y, sin embargo, algunos estudios sugieren la importancia de considerar sus dimensiones de forma separada al

tratarse de un constructo multidimensional (Carretero, Garcés, Ródenas y Sanjosé, 2009; Montorio y otros, 1998; Zarit, 2002). De la misma manera que en este trabajo se ha encontrado respaldo empírico a la importancia de analizar las variables moduladoras multidimensionalmente, sería aconsejable, en futuras investigaciones, analizar el efecto moderador de la carga considerando sus dimensiones por separado. Igualmente, tal y como se ha comentado previamente en la sección de discusión de los Estudio 1 y 2, existen algunas limitaciones relacionadas con las escalas que se han utilizado para medir la autoeficacia percibida del cuidador y los motivos culturales para cuidar.

En segundo lugar, existe la limitación relacionada con la operativización de la dimensión de autoeficacia para controlar pensamientos desagradables (ver Estudio 1), ya que no está claro qué significado tiene el "controlar los pensamientos". Así, los ítems que corresponden a esta dimensión se refieren a una capacidad de controlar pensamientos relacionados con aspectos desagradables del familiar enfermo, la situación de injusticia por ser cuidador o la preocupación por problema futuros por tener que pueden surgir en el cuidado. Sin embargo, podría ser interpretado como la capacidad de lograr que los pensamientos negativos relacionados con el cuidado no interfieran en sus vidas, en el sentido en que los aceptan. Sin embargo, un cuidador también puede interpretar que "controla sus pensamientos" porque usa técnicas de distracción. Sería interesante realizar más estudios que analicen qué conductas concretas lleva a cabo el cuidador cuando "controla" sus pensamientos negativos.

En tercer lugar, la escala para medir motivos para cuidar (ver Estudio 2), esto es, la Escala de Justificaciones Culturales para el Cuidado-Revisada, no es exhaustiva, ya que pueden existir otros posibles motivos para cuidar que no se recogen en dicha escala y que pueden ser importantes a la hora de predecir el malestar del cuidador. Sería interesante tener en cuenta otros motivos que son comunes en los cuidadores, tal y como refleja un

estudio representativo nacional (IMSERSO, 2005), y que no se han incluido en dicha escala, como por ejemplo "porque me dignifica como persona" o "por satisfacción", entre otros. Del mismo modo, existen otro tipo de motivos que han cobrado fuerza fundamentalmente desde la psicología positiva, como los relativos al crecimiento ante la adversidad o la obtención de sentido o propósito en la vida (Leipold, Claudia y Zank, 2008), que sería conveniente considerar.

Por otro lado, tal y como se ha comentado previamente, existen limitaciones en cuanto a los resultados obtenidos al analizar el riesgo de institucionalización de la persona cuidada y la salud física percibida del cuidador (Estudio 3), ya que estas variables han sido evaluadas de manera general, a través de ítems únicos (riesgo de ingreso: "Durante la última semana: ¿En qué medida ha pensado en la posibilidad de ingresar a su familiar en una residencia?; salud percibida; "En la actualidad, ¿cómo considera usted que es su salud?").

Finalmente, existen otras variables que no se han controlado en este estudio y que pueden estar contribuyendo a la explicación de los resultados del mismo, como es si el cuidador toma o no algún tipo de medicación, el nivel socioeconómico de los cuidadores, la calidad de la relación entre el cuidador y la persona cuidada (Ball y otros, 2010; Quinn, Clare y Woods, 2009), así como variables de personalidad del cuidador, como el neuroticismo (Campbell y otros, 2009), o variables positivas, como el crecimiento personal relacionado con el cuidado (Leipold y otros, 2008).

Igualmente, si bien es cierto que en este estudio se han analizado los estresores objetivos en términos de frecuencia de comportamientos problemáticos –variable más contribuye a explicar el malestar del cuidador de acuerdo con algunos estudios (Agüera-Ortiz, Frank-García, Gil y Moreno, 2010)-, y capacidad funcional de la persona cuidada, no se ha controlado la capacidad cognitiva de la persona cuidada, variable que puede estar

afectando a los resultados obtenidos (p.ej., Pinquart y Sörensen, 2007).

10. General conclusions

1. This research highlights the importance of considering the multidimensionality of modulating variables (self-efficacy and motives for caregiving) in order to explain the caregiving stress process.
2. Furthermore, the results suggest that analyzing the combination of different dimensions of the same construct (e.g., extrinsic and intrinsic motives for caring or/and frequency of and satisfaction with leisure) contributes significantly to our understanding of caregivers' distress.
3. In addition, cross-sectional and longitudinal empirical support for the stress and coping model was found. Moreover, this study highlights the usefulness of analyzing modulating variables in different points of the caregiver stress process.
4. Two caregivers' profiles at risk for reporting poorer resources and negative outcomes have been identified:
    a) Caregivers with high levels of extrinsic motives for caring and low levels of intrinsic motives for caring.
    b) Caregivers with low levels of both frequency and satisfaction with behavioral activation or leisure.
5. Considering profiles of caregivers at risk may be useful in order to improve the design and implementation of tailored psychological interventions for dementia caregivers.

11. Referencias Bibliográficas

Agüera-Ortiz, L., Frank-García, A., Gil, P., y Moreno, A. (2010). Clinical progression of moderate-to-severe Alzheimer's disease and caregiver burden: a 12-month multicenter prospective observational study. *International Psychogeriatrics*, en prensa.

Aldao, A., Nolen-Hoeksema, S., y Schweizer, S. (2010). Emotion-regulation strategies across psychopathology: A meta-analytic review. *Clinical Psychology Review, 30*, 217-237.

Alonso, J., Prieto, L., y Antó, J.M. (1995). The Spanish version of the SF-36 health survey: An instrument for measuring clinical results. *Medicina Clínica, 104,* 771-776.

Alzheimer's Disease International (2009). World Alzheimer Report. London: Alzheimer's Disease International.

Arai, Y., Sugiura, M., Washio, M., Miura, H., y Kudo (2001). Caregiver depresión predicts early discontinuation of care for disabled elderly at home. *Psychiatry and Clinical Neurosciences 55,* 379-382.

Arai, Y., Zarit, S.H., Sugiura, M., y Washio, M. (2002). Patterns of outcome of caregiving for the impaired elderly: a longitudinal study in rural Japan. *Aging & Mental Health, 6,* 39–46

Ball, V., Snow, A.L., Steele, A.B., Morgan, R.O., Davila, J.A., Wilson, N., y Kunik, M.E. (2010). Quality of relationships as a predictor of psychosocial functioning in patients with dementia. *Journal of Geriatric Psychiatry and Neurology, 23,* 109-114.

Ballard, C.G, Eastwood, C., Gahir, M., and Wilcock, G.K. (1996). A follow-up of depression in the carers of dementia sufferers. *British Medical Journal, 312,* 947.

Bandura, A. (1997). *Self-efficacy: the exercise of control*. New York: W.H. Freeman.

Bandura, A. (2006). *Guide for constructing self-efficacy scales*. In F. Pajares & T. 295 Urdan (Eds.), Adolescence and education, Volume 5 in the Adolescence and Education series (pp. 307–337). Greenwich, CT: Information Age Publishing.

Bandura, A., Adams, W.E., y Beyer, J. (1977). Cognitive processes mediating behavioral change. *Journal of Personality and Social Psychology, 35*, 125-135.

Baron, R.M., y Kenny, D.A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology, 51*, 1173-1182.

Beach, S.R., Schulz, R., Yee, J.L., & Jackson, S. (2000). Negative and health effects of caring for a disabled spouse: longitudinal findings from the caregiver health effects study. *Psychology and Aging, 15,* 259-271.

Benyamini, Y., y Lomranz, J. (2004). The relationship of activity restriction and replacement with depressive symptoms among older adults. *Psychology and Aging, 19,* 362-366.

Berger, G., Bernhardt, T., Weimer, E., Peters, J., Kratzsch, T., y Frolich, L., (2005). Longitudinal Study on the Relationship Between Symptomatology of Dementia and Levels of Subjective Burden and Depression Among Family Caregivers in Memory Clinic Patients. *Journal of Geriatric Psychiatry and Neurology, 18, 119-128.*

Black, W. and Almeida, O.P. (2004). A systematic review of the association between the Behavioral and Psychological Symptoms of Dementia and burden of care. *International Psychogeriatrics, 16,* 295-315.

Blackledge, J.T., y Hayes , S.C. (2006). Using acceptance and commitment training in the support of parents of children diagnosed with autism. *Child & Family Behavior Therapy, 28,* 1-18

BOE (2006). Ley 39/2006 de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia. Boletín Oficial del Estado, 299, 44142-44156.

Boustani, M., Peterson, B., Hanson, L., Harris, R., y Lohr, K.N. (2003). Screening for dementia in primary care: a summary of the evidence for the U.S. Preventive Services Task Force. *Annals Internal Medicine, 138,* 927-937.

Branstetter-Rost, A., Cushing, C., y Douleh, T. (2009). Personal values and pain tolerance: does a values intervention add to acceptance? Journal of Pain: *Oficial Journal of the American Pain Society 10,* 887-892.

Brookmeyer, R., Johnson, E., Ziegler-Graham, K., y Arrighi, H.M. (2007). Forecasting the global burden of Alzheimer's disease. *Alzheimer's & Dementia 3,* 186 –191.

Burgio, L., Stevens, A., Guy, D., Roth, D.L. y Haley, W.E. (2003). Impact two psychosocial interventions on White and African American family caregivers of individuals with dementia. *The Gerontologist, 43,* 568-579.

Campbell, D.L., y Martin-Mathews, A. (2003). The gendered nature of men's filial care. *The Journals of Gerontology, 58,* 350-358.

Campbell, P., Wright, J., Oyebode, J., Job, D., Crome, P., Bentham, P., Jones, L., y Lendon, C. (2008). Determinants of burden in those who care for someone with dementia.

International Journal of Geriatric Psychiatry, 23, 1078-1085.

Carretero, S., Garcés, J., Ródenas, F., y Sanjosé, V. (2009). The informal caregiver's burden of dependent people: Theory and empirical review. *Archives of Gerontology and Geriatrics 49,* 74–79.

Carruth, A.K. (1996). Motivating factors, exchange patterns, and reciprocity among caregivers of parent with and without dementia. *Research in Nursing and Health, 19,* 409-419.

Carver, C.S, Scheir, M.F. y Weintraub, J.K. (1989). Assesing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 2,* 267-283.

Cho, S., Zarit, S.H., y Chiriboga, D.A. (2009). Wives and daughters: the differential role of day care use in the nursing home placement of cognitively impaired family members. *The Gerontologist, 49,* 57-67.

Chun, M., Knight, B.G., y Youn, G. (2007). Differences in stress and coping models of emotional distress among Korean, Korean-American and White-American caregivers. *Aging and Mental Health, 11*, 20-29.

Cicirelli, V.G. (1993). Attachment and Obligation as Daughters' Motives for Caregiving Behavior and Subsequent Effect on Subjective Burden. *Psychology and Aging, 8*, 144-155.

Clay,O.J., Roth, D.L., Wadley, V.G., and Haley, W.E. (2008). Changes in social support and their impact on psychosocial outcome over a 5-year period for African American and White dementia caregivers. *International Journal of Geriatric Psychiatry, 23,* 857-862.

Coehlo, D.P., Hooker, K., y Bowman, S. (2007). Institutional placement of persons with dementia: what predicts occurrence and timing? *Journal of Family Nursing, 13,* 253-277.

Cohen-Mansfield, J.,y Wirtz, P .W. (2009).The reasons for nursing home entry in an adult day care population: Caregiver reports versus regression results *Journal of Geriatric Psychiatry and Neurology.22, 274-281*.

Consejo de la Unión Europea (2008). Council Conclusions on public health strategies to combat neurodegenerative diseases associated with ageing and in particular Alzheimer's disease. 2916th employmet, social policy, health and cosumer affairs.

Council meeting Brussels, December. Disponible en: http://www.consilium.europa.eu/ueDocs/cms_Data/docs/pressData/en/lsa/104778.pdf

Coon, D.W., Thompson, L., Steffen, A., Sorocco, K., y Gallagher-Thompson, D. (2003). Anger and depression management: Psychoeducational skill training interventions for women caregivers of a relative with dementia. *The Gerontologist, 43*,678–689.

Cooper, C., Blanchard, M., Selwood, A., Walker, Z., and Livingston, G. (2010). Family carers' distress and abusive behaviour: longitudinal study. *The British Journal of Psychiatry: The Journal of Mental Sciences, 196,* 480-485.

Cooper, C., Katona, C., Orrel, M., y Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry, 23,* 929-936.

Croezen, S., Haveman-Nies, A., Alvarado, V.J., Van`T Veer, P., y De Groot, C.P. (2009). Characterization of different groups of elderly according to social engagement activity patterns. *The Journal of Nutrition Health and Aging, 13,* 776-781.

Cuijpers, P. (2005).Depressive disorders in caregivers of dementia patients. *Aging & Mental Health, 9,* 325–330

Cuijpers, P., van Straten, A., y Warmerdam L. (2007). Behavioral activation treatments of depression: a meta-analysis. *Clinical Psychology Review, 27,* 318-326.

Danhauer, S.C., McCann, J.J., Gilley, D.W., Beckett, L.A., Bienias, J.L., Evans, D. A. (2004). Do behavioral disturbances in persons with Alzheimer's Disease predict caregiver depression over time? *Psychology and Aging, 19, 198-202.*

Davis, R.N., y Nolen-Hoeksema, S. (2000). Cognitive inflexibility among ruminators and nonruminators. *Cognitive Therapy and Research, 24,* 699-711.

De Vugt, M.E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., y Verhey, F.R.J. (2005). A prospective study of the effects of behavioral symptoms on the institutionalization of patients with dementia. *International Psychogeriatrics, 17,* 577-589.

Del Barrio, J.L., de Pedro-Cuesta, J., Boix, R., Acosta, J., Bergareche, A., Bermejo-Pareja,F., y otros (2005). Dementia, stroke and Parkinson's disease in Spanish populations: a review of door-to-door prevalence surveys. *Neuroepidemiology, 24,* 179-188.

Díaz-Veiga, P., Montorio, I., y Yanguas, J. (1999). Intervenciones en cuidadores de personas mayores. En M. Izal e I. Montorio (Eds), *Gerontología conductual: Bases para la intervención y ámbitos de aplicación* (pp.159-180). Madrid: Síntesis.

Dilworth-Anderson, P, Goodwin, P.Y. y Williams, S.W. (2004). Can Culture Help Explain the Physical Health Effects of Caregiving Over Time Among African American Caregivers? *Journal of Gerontology: Social Sciences, 59,* 138-145.

Dilworth-Anderson, P., Brummett, H.B., Goodwin, P., Williams, S.W., Williams, R.B., y Siegler, I.C. (2005). Effect of Race on Cultural Justifications for Caregiving. *Journal of Gerontology: Social Sciences, 60*, 257-262.

Dilworth-Anderson, P., Williams I.C., y Gibson, B.E. (2002). Issues of race, ethnicity, and culture in caregiving research: a 20-year review (1980-2000). *The Gerontologist, 42,* 237-272.

Dilworth-Anderson, P., Williams, S.W., y Cooper, T. (1999). Family caregiving to elderly African Americans: caregiver types and structures. *Journals of Gerontology: Psychological Sciences and Social Sciences, 54*, 237-241.

Ducharme, F., Lévesque, L., Zarit, S.H., Lachance, L., y Giroux, F. (2007). Changes in health outcomes among older husband caregivers: a one-year longitudinal study. *The International Journal of Aging and Human Development, 65,* 73-96.

Epstein-Lubow, G., Davis, J.D., Miller, I.W.,y Tremont, G. (2008). Persisting burden predicts depressive symtoms in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology, 21,* 198-203.

Farran, C.J., Keane-Hagerty, E., Salloway, S., Kupferer, S., y Wilken, C.S. (1991). Finding meaning: an alternative paradigm for Alzheimer's disease family caregivers. *The Gerontologist, 31,* 483-489.

Feeney, B.C., y Collins, N.L. (2003). Motivations for caregiving in adult intimate relationships: influences on caregiving behavior and relationship functioning. *Personality and Social Psychology Bulletin, 29*, 950-968.

Ferrara, M., Langiano, E., Di Brango, T., De Vito, E., Di Cioccio, L., y Bauco, C. (2008). Prevalence of stress, anxiety and depression in with Alzheimer caregivers. *Health and Quality of Life Outcome, 6,* 6-93.

Ferri, C.P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M., Hall, K., Hasegawa, K., Hendrie, H., Huang, Y., Jorm, A., Mathers, C., Menezes, P.R., Rimmer, E., y Scazufca, M. (2005). Global prevalence of dementia: a Delphi consensus study. *Lancet, 366,* 2112–2117.

Fisher, P.A., y Laschinger, H.S. (2001). A relaxation training program to increase self-efficacy for anxiety control in Alzheimer family caregivers. *Holistic Nursing*

Practice, 15, 47-58.

Fortinsky, R.H., Kercher, K., y Burant, C.J. (2002). Measurement and correlates of family caregiver self-efficacy for managing dementia. *Aging & Mental Health, 6*, 153–160.

Gallagher-Thompson, D., Coon, D.W., Solano, N., Ambler, C., Rabinowitz, Y., y Thompson, L.W. (2003). Change in indices of distress among Latino and Anglo female caregivers of elderly relatives with dementia: site-specific results from the REACH national collaborative study. *The Gerontologist, 43,* 580-591.

Gallagher-Thompson, D., Gray, H.L., Tang, P.C.Y., Pu, C.Y., Leung, L.Y.L., Wang, P.C., et al. (2007). Impact of In-Home behavioural management versus telephone support to reduce depressive symptoms and perceived stress in Chinese caregivers: results of a pilot study. *American Journal of Geriatric Psychiatry 15*, 425–434.

Gallagher-Thompson, D., Lovett, S., Rose, J., McKibbin, C., Coon, D., Futterman, A., y Thompson, L.W. (2000). Impact of psycho-educational interventions on distressed family caregivers. *Journal of Clinical Geropsychology, 6,* 91-110.

Garcés, J., Carretero, F., Ródenas, S., y Alemán, C. (2010). A review of programs to alleviate the burden of informal caregivers of dependent persons. *Archives of Gerontology and Geriatrics, 50,* 254–259.

Gaugler, F.Y., Krichbaum, K.,y and Wyman, J.F. (2009). Predictors of nursing home admission for persons with dementia. *Medical Care, 47,* 191-198.

Gaugler, J.E. (2010). The longitudinal ramifications of stroke caregiving: A systematic review. *Rehabilitation Psychology, 55,* 108-125.

Gaugler, J.E., Kane, R.L., Kane, R.A., y Newcomer, R. (2005). The longitudinal effects of early behavior problems in the dementia caregiving career. *Psychology and Aging, 20*, 100-116.

Gaugler, J.E., Kane, R.L., Kane, R.A., y Newcomer, R. (2006). Predictors of institutionalization in Latinos with dementia. *Journal of Cross-Cultural Gerontology, 21,* 139-155.

Gignac, M.A.M., y Gottlieb, B.H. (1996). Caregivers´ appraisals of efficacy in coping with dementia. *Psychology and Aging, 11,* 214-225.

Gilliam, C. M., y Steffen, A. M. (2006). The relationship between caregiving self-efficacy and depressive symptoms in dementia family caregivers. *Aging and Mental Health, 10*, 79–86.

Gitlin, L.N., Corcoran, M., Martindale-Adams, J., Malone, C., Stevens, A. y Winter, L. (2000). Identifying Mechanisms of Action: Why and How Does Intervention Work?. En R. Schulz (ed.), *Handbook on Dementia Caregiving. Evidence-Based Interventions for Family Caregivers*. Nueva York: Springer.

Gotlieb, B.H., y Rooney, J.A. (2004). Coping effectiveness: Determinants and relevance to the mental health and affect of family caregivers of persons with dementia. *Aging and Mental Health, 8*, 364-373.

Gottlieb, B.H. y Wolfe, J. (2002). Coping with family caregiving to persons with dementia: a critical review. *Aging & Mental Health, 6,* 325-342.

Gregg, J.A., Callaghan, C.M., Hayes, S.C., y Glenn-Lawson, J.L. (2007). Improving diabetes self-management through acceptance, mindfulness, and values: a randomized controlled trial. *Journal of Consulting and Clinical Psychology, 75,* 336-343.

Gross, J.J., y John, O.P. (2003). Individual Differences in Two Emotion Regulation Processes: Implications for Affect, Relationships, and Well-Being. *Journal of Personality and Social Psychology, 85,* 348-362.

Haley, W.E., Levine, E.G., Brown, L., y Bartolucci, A.A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging, 2,* 323-330.

Haley, W.E., Roth, D.L., Coleton, M.I., Ford, G.R., West, C.A., Collins, R.P e Isobe, T.L (1996). Appraisal, Coping and Social Support as Mediators of Well-Being in Black and White Family Caregivers of Patients With Alzheimer´s Disease. Journal of *Consulting and Clinical Psychology, 64,* 121-129.

Hayes, S.C., Strosahl, K., y Wilson, K.G. (1999). *Acceptance and Commitment Therapy: An experiential approach to behavior change*. New York: Guilford Press.

Heru, A.M.,y Ryan, C.E. (2006). Family Functioning in the Caregivers of Patients with Dementia: One-Year Follow-up. *Bulletin of the Menninger Clinic, 70,* 222-231.

Hilgeman, M.M., Durkin, D.W., Sun, F., DeCoster, J., Allen, R.S., Gallagher-Thompson, D. y Burgio, L.D. (2009). Testing a Theoretical Model of the Stress Process in Alzheimers Caregivers with Race as a Moderator. *The Gerontologist, 49,* 248-261.

Hirano A., Suzuki, Y., Kuzuya, M., Unishi, J., Hasegawa, J., Ban, N., y Umegaki, H. (in press). Association between the caregivers' burden and physical activity in community-dwelling caregivers of dementia patients. *Archives of Gerontology and*

Geriatrics.

Holley, C.K., and Mast, B.T. (2010). Predictors of anticipatory grief in dementia caregivers. *Clinical Gerontologist: The Journal of Aging and Mental Health, 33*, 223-236.

Holmbeck, G. N. (2002). Post-hoc probing of significant moderational and mediational effects in studies of pediatric populations. *Journal of Pediatric Psychology, 27,* 87–96.

Hooker, K., Bowman, S.R., Coehlo, D.P., Lim, S.R., Kaye, J., Guariglia, R., y Li, F. (2002). Behavioral change in persons with dementia: Relationships with mental and physical health of caregivers. *Journals of Gerontology: Psychological Sciences and Social Sciences, 57B*, 453-460.

Hsu, H., y Shyu,Y.L. (2003). Implicit exchanges for family caregiving for frail elders in Taiwan. *Qualitative Health Research, 13,* 1078-1093.

IMSERSO (2002). Envejecer en España II. Asamblea Mundial sobre el envejecimiento. Madrid: Instituto de Migraciones y Servicios Sociales.

IMSERSO (2005). *Cuidados a las personas mayores en los hogares españoles. El entorno familiar* [Caring for older persons in Spanish homes. The family environment]. Madrid: IMSERSO.

IMSERSO (2010). Encuesta mayores 2010. Madrid: IMSERSO.

Izal, M., Nuevo, R., Montorio, I., y Pérez-Rojo, G. (2009). Method of recruitment and the scores of self-report measures: the example of worry in the elderly. Archives of *Gerontology and Geriatrics, 48,* 45-49.

Jackson, B. and Nolen-Hoeksema, S. (1998). *The Emotion-Focused Coping Questionnaire.* Manuscript in progress.

Jacobson, N.S., Dobson, K.S., Truax, P.A., Addis, M.E., Koerner, K., Gollan, J.K., et al. (1996). A component analysis of cognitive-behavioral treatment for depression. *Journal of Consulting and Clinical Psychology, 64,* 295-304.

Janevit, M.R., y Connell, C.M. (2001). Racial, ethnic and cultural differences in the dementia caregiving experience: recent findings. *The Gerontologist, 41,* 334-347.

Jefferson, A. L., Cahn-Weiner, D., Boyle, P., Paul, R.H., Moser, D.J., Gordon, N. C., Ronald A. (2006). Cognitive predictors of functional decline in vascular dementia. *International Journal of Geriatric Psychiatry, 21, 752-754.*

Joling, K.J., van Hout, H.P.J; Schellevis, F. G. van der, H., Henriette, E., Scheltens, P. Knol,

D.L.,y van Marwijk, H.W. J.(2010). Incidence of depression and anxiety in the spouses of patients with dementia: A naturalistic cohor study of recorded morbidity with a 6-year follow-up. *The American Journal of Geriatric Psychiatry, 18,*146-153.

Jönsson, L., y Wimo, A. (2009). The cost of dementia in Europe: a review of the evidence, and methodological considerations. *Pharmacoeconomics, 27,* 391-403.

Kabitsi, N., y Powers, D.V. (2002). Spousal motivations of care for demented older adults: a cross-cultural comparison of Greek and American female caregivers. *Journal of Aging Studies, 16,* 383-399.

Kaufman, A.V., Kosberg, J.I., Leeper, J.D., y Tang, M. (2010). Social support, caregiver burden, and life satisfaction in a sample of rural African American and White caregivers of older persons with dementia. *Journal of Gerontological Social Work, 53,* 251-269.

Kim, J., Knight, B.G., y Flynn-Longmire, C.V. (2007). The role of familism in stress and coping processes among African American and White dementia caregivers: Effects on mental and physical health. *Health Psychology, 26,* 564-576.

Kim, J.H., y Knight, B.G. (2008). Effects of caregiver status, coping styles, and social support on the physical health of Korean American caregivers. *The Gerontologist, 48*, 287-299.

Kneebone, I.I. and Martin, P.R. (2003). Coping and caregivers of people of dementia. *British Journal of Health and Psychology, 8*, 1-17.

Knight, B., y Losada, A. (2010). Family Caregiving for Cognitively or Physically Frail Older Adults: Theory, Research, and Practice.In K.W. Schaie y S.L. Willis (Eds.), Handbook of the Psychology of Aging (7ª ed.). New York: Academic Press.

Knight, B.G., y Sayegh, P. (2010). Cultural values and caregiving: the updated Sociocultural Stress and Coping Model. *Journal of Gerontology: Psychological Sciences, 65,* 5-13.

Knight, B.G., Silverstein, N., McCallum, T.J., y Fox, L.S. (2000). A sociocultural stress and coping model for mental health outcomes among African American caregivers in Southern California. *Journal of Gerontology: Psychological Sciences and Social Sciencies, 55*(3), 142-150.

Knussen, C. Tolson, D., Brogan, C. A., Swan, I.R.C, Stott, D.J., Sullivan, F. (2008). Family caregivers of older relatives: Ways of coping and change in distress. *Psychology, Health & Medicine, 13,* 274-290.

Kraemer, H.C. and Blasey, C.M. (2004). Centring in regression analyses: a strategy to

prevent errors in statistical inference. *International Journal of Methods in Psychiatric Research, 13,* 141-151.

Lamura, G., Mnich E., Nolan, M., Wojszel, B., Krevers B., Mestheneos, L., y Döhner, H. (2008). Family carers´experiences using support services in Europe: empirical evidence from the EUROFAMCARE Study. *The Gerontologist, 48,* 752-771.

Laserna, J.A., Castillo, A., Peláez, E.M., Navío, L.F. Torres, C.J., Rueda, S., Ramírez, M.N. y Pérez, M. (1997). Alteraciones emocionales y variables moduladoras en familiares-cuidadores de enfermos de Alzheimer. *Psicología Conductual, 5,* 365-375.

Lazarus, R.S., y Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer Publishing Company.

Lawton, M.P., Kleban, M.H., Moss, M., Rovine, M., y Glicksman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontology: Psychological Sciences, 44,* 61-71.

Leipold, B., Claudia, S., y Zank, S. (2008). Personal growth and cognitive complexity in caregivers of patients with dementia. *European Journal of Ageing, 5,* 203-214.

Lewinsohn, P.M. (1975). Engagement in pleasant activities and depression level. *Journal of Abnormal Psychology, 84*, 729-731.

Li, L.W., Seltzer, M.M., y Greenberg, J.S. (1999). Change in depressive symptoms among daughter caregivers: An 18-month longitudinal study. *Psychology and Aging, 14,* 206-219.

López J., López-Arrieta, J., y Crespo, M. (2005). Factors associated with the positive impact of caring for elderly and dependent relatives. *Archives of Gerontology and Geriatrics, 41,* 81–94.

Losada, A., Márquez-González, M., y Romero-Moreno, R. (in press). Mechanism of action of a psychological intervention for dementia caregivers: effects of behavioural activation and dysfunctional thoughts modification. *International Journal of Geriatric Psychiatry.*

Losada, A., Márquez-González, M., Knight, B., Yanguas, J., Sayegh, P. and Romero-Moreno, R. (2010). Psychosocial factors and caregivers´ distress: Effects of familism and dysfunctional thoughts. *Aging and Mental Health, 14,* 193-202.

Losada, A., Márquez-González, M., Peñacoba, C., y Romero-Moreno, R. (2010). Development and validation of the Caregiver Guilt Questionnaire. *International Psychogeriatrics, 22,* 650-660.

Losada, A., Pérez-Peñaranda, A., Rodríguez, E., Gómez, M.A., Ballesteros, C., Ramos, I.,

Campo, M.A. y García, L. (2010). Leisure and distress in caregivers for elderly patients. *Archives of Gerontology and Geriatrics, 50*, 347-350.

Loucks-Atkinson, A., Douglas, A., y Williamson, G.M. (2006). Activity restriction and well-being in middle-aged and older caregivers. *Topics in Geriatric Rehabilitation, 22,* 269-282.

Lund, D.A., Utz, R., Caserta, M.S., y Wright, S.D. (2009). Examining what caregivers do during respite time to make respite more effective. *Journal of Applied Gerontology, 28,* 109-131.

Lundgren, T., Dahl, J., y Hayes, S.C. (2008). Evaluation of mediators of change in the treatment of epilepsy with acceptance and commitment therapy. *Journal of Behavior Medicine, 31,* 225-235.

Lutzky, S.M. y Knight, B. G. (1994). Explaining gender differences in caregiver distress: the roles of emotional attentiveness and coping styles. *Psychology and Aging, 9,* 513-519.

Lyonette, C., y Yardley, L. (2003). The influence on carer wellbeing of motivations to care for older people and the relationship with the care recipient. *Aging and Society, 23*, 487-506.

Lyons, K.S., Steward, B.J., Archbold, R.N., y Carter, J.H. (2009). Optimism, Pessimism, Mutuality, and Gender: Predicting 10-Year Strain in Parkinson's Disease Spouses. *The Gerontologist, 49,* 378-387.

Mahoney, F.L., y Barthel, D.W. (1965) Functional evaluation: The Barthel Index. *State Journal, 4,* 61-65.

Márquez-González, M., Losada, A., Izal, M., Pérez-Rojo, G., y Montorio, I. (2007). Modification of dysfunctional thoughts about caregiving in dementia family caregivers: description and outcomes of an intervention programme. *Aging and Mental Health, 11*, 616-625.

Márquez-González, M., Losada, A., López, J., y Peñacoba, C. (2009). Reliability and Validity of the Spanish Version of the Revised Scale for Caregiving Self-Efficacy. *Clinical Gerontologist, 32*, 1–11.

Márquez-González, M., Losada, A., Peñacoba, C. y Romero-Moreno, R. (2009). El optimismo como factor moderador de la relación entre el estrés y la depresión de los cuidadores informales de personas mayores dependientes. *Revista Española de*

Geriatría y Gerontología, 44, 251-255.

Márquez-González, M., Romero-Moreno, R. and Losada, A. (in press). Caregiving issues in a therapeutic context: new insights from the Acceptance and Commitment approach. In K. Laidlaw and N. Pachana, (Eds.). *Casebook of Clinical Geropsychology: International Perspectives on Practice*. New York: Oxford University Press.

Martín-Carrasco, M., Martín, M.F., Valero, C.P., Millán, P.R., García, C.I., Montabán, S.R., Vázquez, A.L., Piris, S.P., y Vilanova, M.B. (2009). Effectiveness of a psychoeducational intervention program in the reduction of caregiver burden in Alzheimer's disease patients' caregivers. *International Journal of Geriatric Psychiatry, 24,* 489-499.

Mausbach B.T., Coon, D.W., Patterson, T.L., y Grant, I. (2008). Engagement in activities is associated with affective arousal in Alzheimer´s caregivers: a preliminary examination of the temporal relations between activity and affect. *Behavior Therapy, 39,* 366-374.

Mausbach, B., Patterson, T., Rabinowitz, Y., Grant, I., Schulz, R. (2007) .Depression and distress predict time to cardiovascular disease in dementia caregivers. *Health Psychology 26*, 539–544.

Mausbach, B., Patterson, T., Rabinowitz, Y., von Känel, R., Mills, P.J., Dimsdale, J.E., Ancoli-Israel, S., y Grant, I. (2007). The attenuating effect of personal mastery on the relations between stress and Alzheimer caregiver health: A five-year longitudinal analysis. *Aging and Mental Health, 11,* 637-644.

Mausbach, B.T., Cardenas, V., Goldman, S., y Patterson, T. (2007). Symptoms of psychosis and depression in middle-aged and older adults with psychotic disorders: the role of activity satisfaction. *Aging and Mental Health, 11,* 339-345.

Mausbach, B.T., Patterson, T.L., y Grant, I. (2008). Is depression in Alzheimer's caregivers really due to activity restriction? A preliminary meditational test of the Activity Restriction Model. *Journal of Behavior Therapy and Experimental Psychiatry, 39,* 459-466.

Mausbach, B.T., Roepke, S.K., Depp, C.A., Moore, R., Patterson, T.L., y Grant, I. (in press). Integration of the Pleasant Events (PE) and Activity Restriction (AR) Models: Development and Validation of a "PEAR" Model of Negative Outcomes in Alzheimer´s Caregivers. *Behavior Therapy.*

Mausbach, B.T., Roepke, S.K., Depp, C.A., Patterson, T.L., y Grant, I. (2009). Specificity of

cognitive and behavioral variables to Positive and Negative Affect. *Behaviour Research and Therapy, 47,* 608-615.

Mausbach, B.T., Roepke, S.K., Depp, C.D., Patterson, T.L., y Grant, I. (2009). Specificity of cognitive and behavioral variables to positive and negative affect. *Behaviour Research and Therapy, 47,* 608-615.

McNair, D., Lorr, M. and Droppleman, L. (1971). *Profile of Mood States. Manual*. San Diego: Educational and Industrial Testing Service.

Ministerio de Trabajo y Asuntos Sociales (2005). *Libro Blanco de la Dependencia*. Madrid: Ministerio de Trabajo y Asuntos Sociales.

Mittelman, M.S., Roth, D.L., Haley, W.E., y Zarit, S.H. (2004). Effects of a caregiver intervention on negative caregiver appraisalof behavior problems in patients with Alzheimer's disease: results of a randomized trial. *Journal of Gerontology: Social Sciences, 59,* 27-34.

Montorio, I., Izal, M., López-López, A., y Colodrón, N. (1998). La Entrevista de Carga del Cuidador. Utilidad y validez del concepto de carga. *Anales de Psicología, 14,* 229-248.

Nolen-Hoeksema, S., Wisco, B.E., y Lyubomirsky , S. (2008). Rethinking rumination. *Perspectives on Psychological Sciences, 3,* 400-424.

Oken, B.S., Fonareva, I., Haas, M., Wahbeh, H., Lane, J.B., Zajdel, D., y Amen, A. (2010). Pilot controlled trial of mindfulness meditation and education for dementia caregivers. *Journal of Alternative and Complementary Medicine, 16,* 1031-1038.

O'Rourke, N., y Tuokko, H.A. (2004). Caregiver burden and depressive symptomatology: The association between constructs over time. *Clinical Gerontologist: The Journal of Aging and Mental Health, 27, 41-52.*

O'Rourke, N., Cappeliez, P.,y Neufeld, E. (2008). Recurrent depressive symtomatology and physical health: A 10-year study of informal caregivers of persons with dementia. *The Canadian Journal of Psychiatry, 52, 434-441.*

Pastor, M.V.Z., del Serb,T., Rodríguez, A.L., García, M.J.Y.,Yébenesc, Domingo, J., y Otero, A.P. (2003). Demencia no detectada y utilización de los servicios sanitarios: implicaciones para la atención primaria. *Atención Primaria, 31,* 581-586.

Pearlin, L.I., Mullan, J.T., Semple, S.J., y Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30,* 583-594.

Pedro-Cuesta, J., Virués-Ortega, J., Vega, S., Seijo-Martínez, M., Saz, P., Rodríguez-Cuesta, J., … y del Barrio, J.L. (2009). Prevalence of dementia and major dementia subtypes in Spanish populations: a reanalysis of dementia prevalence surveys, 1990-2008. *BMC Neurology, 19,* 9-55.

Peeters, J.M.,Van Beek, A.P., Meerveld, J.H., Spreeuwenberg, P.M., y Francke, A.L. (2010). Informal caregivers of persons with dementia, their use of and needs for specific professional support: a survey of the National Dementia Programme. *BMC Nursing,* en prensa.

Perren, S., Schmid, R., y Wettstein, A. (2006). Caregivers' adaptation to change: The impact of increasing impairment of persons suffering from dementia on their caregivers' subjective well-being. *Aging & Mental Health,10,* 539–548

Pinquart, M. y Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. *The Gerontologist, 45*, 90-106.

Pinquart, M. y Sörensen, S. (2006). Helping caregivers of persons with dementia: Which interventions work and how large are their effects? *International Psychogeriatrics, 11,* 1-19.

Pinquart, M., y Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging 18,* 250-267.

Pinquart, M., y Sörensen, S. (2006). Gender Differences in Caregiver Stressors, Social Resources, and Health: An Updated Meta-Analysis. *Journal of Gerontology: Psychological Sciences, 61,* 33-45.

Pinquart, M., y Sörensen, S. (2007). Correlates of physical health of informal caregivers: a meta-analysis. *Journal of Gerontology: Psychological Sciences, 62*, 126-137.

Pruchno, R., Brill, J., Shands, Y., Gordon, J., Genderson, M., Rose, M., y Cartwright, F. (2008). Convenience Samples and Caregiving Research: How Generalizable Are the Findings? *The Gerontologist, 48*, 820-7.

Quinn, C., Clare, L., y Woods, R.T. (2010). The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: a systematic review. *International Psychogeriatrics, 22*, 43-55.

Quinn, C., Clare, L., y Woods, B. (2009). The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: a systematic

review. *Aging and Mental Health, 13,* 143-154.

Rabinowitz, Y.G., Mausbach, B.T., y Gallagher-Thompson, D. (2009). Self-efficacy as a moderator of the relationship between care recipient memory and behavioral problems and caregiver depression in female dementia caregivers. *Alzheimer Disease and Associated Disorders, 23*, 389-394.

Rabinowitz, Y.G., Mausbach, B.T., Coon, D.W., Depp, C., Thompson, L.W., y Gallagher-Thompson, D. (2006). The moderating effect of self-efficacy on intervention response in women family caregivers of older adults with dementia. American Journal of *Geriatric Psychiatry, 14*, 642–649.

Rabinowitz, Y.G., Mausbach, B.T., Thompson, L.W., y Gallagher-Thompson, D. (2007). The relationship between self-efficacy and cumulative health risk associated with health behavior patterns in female caregivers of elderly relatives with Alzheimer´s dementia. *Journal of Aging and Health, 19*, 946-964.

Radloff, L.S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1,* 385-401.

Raes, F., Hoes, D., Van Gucht D., Kanter, J.W., y Hermans, D. (2010). The Dutch version of the behavioral activation for depression scale (BADS): Psychometric properties and factor structure. *Journal of Behavior Therapy and Experimental Psychiatry, 41,* 246-250.

Raj, J.P., Manigandan, C., y Jacob, K.S. (2006). Leisure satisfaction and psychiatric morbidity among informal carers of people with spinal cord injury. *Spinal Cord, 44,* 676-679.

Rivera, B., Casal, B., y Currais, L. (2008). Estudio económico del tiempo de cuidado informal como factor de producción de salud en el enfermo de Alzheimer no institucionalizado. Colección Estudios Económicos. Serie Economía de la Salud y Hábitos de Vida. CÁTEDRA Fedea – la Caixa

Romero-Moreno, R., Márquez-González, M., Losada, A., y López, J. (in press). Motives for caring: relationship to stress and coping dimensions. *International Psychogeriatrics.*

Romero-Moreno, R., Mausbach, B.T., Losada, A., Márquez-González, M., Patterson, T.L., y López, J. (in press). Analysis of the moderating effect of self-efficacy domains in different points of the dementia caregiving process. *Aging and Mental Health.*

Rose, B.M., Holmbeck, G.N., Coakley, R.M., y Franks, E.A. (2004). Mediator and moderator effects in developmental and behavioral pediatric research. *Developmental*

and Behavioral Pediatrics, 25, 58-67.

Roth, D.L., Haley, W.E., Owen, J.E., Clay, O.J., and Goode, K.T. (2001). Latent growth models of the longitudinal effects of dementia caregiving: a comparison of African American and White family caregivers. *Psychology and Aging, 16,* 427-436.

Salovey, P., Mayer, J.D., Goldman, S.L., Turvey, C. and Palfai, T.P. (1995). Emotional attention, clarity, and repair: Exploring emotional intelligence using the Trait Meta-Mood Scale. In J.W. Pennebaker, (Eds). *Emotion, Disclosure, and Health* (pp.125-154). Washington, D.C.: American Psychological Assn.

Salovey, P., Mayer, J.D., Goldman, S.L., Turvey, C., y Palfai, T.P. (1995). Emotional attention, clarity, and repair: Exploring emotional intelligence using the Trait Meta-Mood Scale. In J.W. Pennebaker, (Eds). *Emotion, Disclosure, and Health* (pp.125-154). Washington, D.C.: American Psychological Assn.

Sayegh, P. y Knight, B.G. (en prensa). The Effects of Familism and Cultural Justification on the Mental and Physical Health of Family Caregivers. *Journals of Gerontology: Psychological Sciences*, in press

Schoenmakers, B., Buntinx, F., y De Lepeleire, J. (2009). The relation between care giving and the mental health of caregivers of demented relatives: A cross-sectional study. *European Journal of General Practice, 15,* 99-106.

Schoenmakers, B., Buntinx, F., y Delepeleire, J. (2010). Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas, 66,* 191-200.

Schulz, R., and Williamson, G.M. (1991). A 2-year longitudinal study of depression among Alzheimer's caregivers. *Psychology and Aging, 6,* 569-578.

Schulz, R., Martire, L.M. y Klinger, J.N. (2005). Evidence-based caregiver interventions in geriatric psychiatry. *Psychiatrics Clinics of North America, 28,* 1007-1038.

Schulz, R., McGinnis, K.A, Zhang, S., Martire, L.M.,Hebert, R.S., Beach, S.R., Zdaniuk, B., Czaja, S.J.,y Belle, S.H. (2008). Dementia patient suffering and caregiver depression. *Alzheimer Disease and Associated Disorders, 2,* 170-176.

Schulz, R., O´Brien, A.T., Bookwala, J., y Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *The Gerontologist, 35*, 771-791.

Searson, R., Hendry, A. M, Ramachandran, R., Burns, A., y Purandare, N. (2008). Activities enjoyed by patients with dementia together with their spouses and psychological

morbidity in carers. *Aging & Mental Health, 12,* 276-282.

Shaw, W.S., Patterson, T.L., Semple, S.J., Ho, S., Irwin, M.R., Haugler, R.L., y Grant, I. (1997). Longitudinal analysis of multiple indicators of health decline among spousal caregivers. *Annals of Behavioral Medicine, 19,* 101-109.

Shaw, W.S., Patterson, T.L., Shirley, J., Sempleb, J.E., Dimsdale, M., Michael G. Zieglerb, M.G. y Grant, I. (2003). Emotional expressiveness, hostility and blood pressure in a longitudinal cohort of Alzheimer caregivers. *Journal of Psychosomatic Research 54,* 293– 302.

Spielberger, C.D. (1988). *State-trait anger expression inventory. Research edition*. Odessa, FL: Psychological Assessment Resources.

Steffen, A.M., McKibbin, C., Zeiss, A.M., Gallagher-Thompson, D., y Bandura, A. (2002). The Revised Scale for Caregiving Self-Efficacy: Reliability and Validity Studies. *Journal of Gerontology: Psychological Sciences 57,* 74–86.

Stevens, A.B., Coon, D., Wisniewski, S., Vance, D., Arguelles, S., Belle, S., Mendelsohn, A., Ory, M. y Haley, W. (2004). Measurement of leisure time satisfaction in family caregivers. *Aging and Mental Health, 8*, 450-459.

Tabachnick, B.G., y Fidell, L.S. (1996). *Using multivariate statistics* (3rd ed.). New York: Harper Collins.

Taylor, D.H., Ezell, M., Kuchibhatla, M., Østbye, T., y Clipp, E.C. (2008). Identifying Trajectories of Depressive Symptoms for Women Caring for Their Husbands with Dementia. *Journal of the American Geriatrics Society, 56,* 322-327.

Teri, L. (1997). Behavior and caregiver burden: behavioral problems in patients with Alzheimer disease and its association with caregiver distress. *Alzheimer Disease and Associated Disorders, 11*, 35-38.

Teri, L., McCurry, S.M., Logsdon, R., y Gibbons, L.E. (2005). Training community consultants to help family members improve dementia care: a randomized controlled trial. *The Gerontologist, 45*, 802-811.

Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., y Vitaliano, P.P. (1992). Assessment of Behavioral Problems in Dementia: The Revised Memory and Behavior Problems Checklist. *Psychology and Aging, 7,* 622-631.

Thompson, E.J., Futterman, A.M., Gallagher-Thompson, D., Rose, J.M., y Lovett, S.B. (1993). Social support and caregiving burden in family caregivers of frail elders.

Journal of Gerontology, 48, 245-254.

Thompson, L. W., Gallagher, D., and Lovett, S. (1992). Increasing Life Satisfaction Class Leaders' and Participant Manuals, VA Palo Alto Health Care System and Stanford University School of Medicine, Palo Alto, CA.

Thompson, L.W., Solano, N., Kinoshita, L., Coon, D. W., Mausbach, B., y Gallagher-Thompson, D. (2002). Pleasurable activities and mood: Differences between Latina and Caucasian dementia caregivers. *Journal of Mental Health and Aging, 8,* 211-224.

Thomsen, D.K., Jorgensen, M.M., Mehlsen, M.Y., y Zachariae, R. (2004). The influence of rumination and defensiveness on negative affect in response to experimental stress. *Scandinavian Journal of Psychology, 45,* 253-258.

Van Den Wijngaart, M.A, Vernooij-Dassen, M.J., y Felling, A.J. (2007). The influence of stressors, appraisal and personal conditions on the burden of spousal caregivers of persons with dementia. *Aging and Mental Health, 11*, 626-636.

Vitaliano, P.P., Young, H.M., y Zhang, J. (2004). Is caregiving a risk factor for illness? *Current Directions in Psychological Science, 13*, 13-16.

Walker, A.J., Pratt, C.C., Shin, H., y Jones, L.L. (1990). Motives for parental caregiving and relationship quality. *Family Relations, 39*, 51-56.

Warr, P., Butcher, V., y Robertson, I. (2004). Activity and psychological well-being in older people. *Aging and Mental Health, 8,* 172-183.

Wassertheil-Smoller, S., Applegate, W.B., Berge, K., Chang, C.J., Davis, B.R., Grimm, R.J., Kostis, J., Pressel, S., Schron, E., (1996). Change in depression as a precursor of cardiovascular events. SHEP Cooperative Research Group (Systoloc Hypertension in the elderly). *Archives of Internal Medicine ,156*, 553–561.

Weiss, C. O., González, H. M., Kabeto, M. U. y Langa, K. M. (2005). Differences in amount of informal care received by non-Hispanic whites and Latinos in a nationally representative sample of older Americans. *Journal of the American Geriatrics Society, 53,* 146-151.

Whitlatch, C.J. y Noelker, L.S (1996). Caregiving and caring. *Encyclopedia of Gerontology, 1,* 253-268.

Williamson, G.M., y Schulz, R. (1992). Pain, activity restriction, and symptoms of depression among community-residing elderly adults. *Journal of Gerontology: Psychological Sciences, 47,* 367-372.

Williamson, G.M., y Shaffer, D.R. (2000). The activity restriction model of depressed affect:

Antecedents and consequences of restricted normal activities. In G.M. Williamson, D.R. Shaffer y P.A. Parmelee (Eds.), *Physical Illness and depression in older adults: A handbook of theory, research, and practice* (pp. 173-200). New York: Kluwer Academic/Plenium.

Wright, L.K. (1994). AD spousal caregivers. Longitudinal changes in health, depression, and coping. *Journal of Gerontological Nursing, 20,* 33-48.

Zarit, S.H., (2002). Caregiver's burden. In: Andrieu, S., Aquino, J.P. (Eds.), Family and Professional Carers: Findings Lead to Action. Serdi Edition and Fondation Médéric Alzheimer, Paris, pp. 20–24.

Zarit, S.H., Femia, E.E., Kim, K., y Whitlatch, C.J. (2010). The structure of risk factors and outcomes for family caregivers: implications for assessment and treatment. *Aging and Mental Health, 14,* 220-231.

Zarit, S.H., Reever, R., y Bach-Peterson, J. (1980). Relatives of impaired elderly: Correlates of feelings of burden. *The Gerontologist, 20,* 649, 655.

Zeiss, A.M., Gallagher-Thompson, D., Lovens, S., Rose, J., y McKibbin C. (1999). Self-Efficacy as a Mediator of Caregiver Coping: Development and Testing of an Assessment Model. *Journal of Clinical Geropsychology, 5*, 221-230.

Anexos

Anexo I: Instrumentos de Evaluación

Autoeficacia

Por favor, estamos interesados en saber hasta qué punto usted está seguro de ser capaz de realizar las siguientes actividades. Puntúe su grado de confianza de 0 a 100 utilizando la escala que se le propone. (Indique si algo es absolutamente no aplicable –por ejemplo, no le ocurre o no lo piensa- a su situación marcando la opción no aplicable N/A).

1.- Cuando su familiar olvida su rutina diaria y pregunta cuándo es la hora de comer justo después de haber comido, ¿hasta qué punto cree que usted es capaz de responderle sin levantarle la voz? (aclarar que "responderle" puede ser directamente o con una distracción)

N/A	0	10	20	30	40	50	60	70	80	90	100
□	□	□	□	□	□	□	□	□	□	□	□
	No soy capaz de hacerlo en absoluto				Soy capaz de hacerlo moderadamente				Estoy seguro de que soy capaz de hacerlo		

2.- Cuando se enfada con su familiar porque repite la misma pregunta una y otra vez, ¿hasta qué punto cree que usted es capaz de decirse cosas para tranquilizarse a usted mismo?

N/A	0	10	20	30	40	50	60	70	80	90	100
□	□	□	□	□	□	□	□	□	□	□	□
	No soy capaz de hacerlo en absoluto				Soy capaz de hacerlo moderadamente				Estoy seguro de que soy capaz de hacerlo		

3- Cuando su familiar se queja sobre cómo le está tratando, ¿hasta qué punto cree que usted es capaz de responder sin discutir (por ejemplo tranquilizándole o distrayéndole)?

N/A	0	10	20	30	40	50	60	70	80	90	100
□	□	□	□	□	□	□	□	□	□	□	□
	No soy capaz de hacerlo en absoluto				Soy capaz de hacerlo moderadamente				Estoy seguro de que soy capaz de hacerlo		

4- ¿Cuando su familiar le pregunta 4 veces durante la primera hora después de comer que cuándo está lista la comida, hasta qué punto cree que usted es capaz de responderle sin levantar la voz?

N/A	0	10	20	30	40	50	60	70	80	90	100
□	□	□	□	□	□	□	□	□	□	□	□
	No soy capaz de hacerlo en absoluto				Soy capaz de hacerlo moderadamente				Estoy seguro de que soy capaz de hacerlo		

5- ¿Cuando su familiar le interrumpe por cuarta vez mientras está haciendo la cena, hasta qué punto cree que usted es capaz de responderle sin levantar la voz?

N/A	0	10	20	30	40	50	60	70	80	90	100
□	□	□	□	□	□	□	□	□	□	□	□
	No soy capaz de hacerlo en absoluto				Soy capaz de hacerlo moderadamente				Estoy seguro de que soy capaz de hacerlo		

6- ¿Hasta qué punto cree que usted es capaz de controlar el pensar sobre los aspectos negativos o desagradables de cuidar de su familiar?

N/A	0	10	20	30	40	50	60	70	80	90	100
□	□	□	□	□	□	□	□	□	□	□	□
	No soy capaz de hacerlo en absoluto				Soy capaz de hacerlo moderadamente				Estoy seguro de que soy capaz de hacerlo		

7- ¿Hasta qué punto cree que usted es capaz de controlar el pensar sobre lo injusto que es que usted tenga que aguantar esta situación (de cuidar de su familiar)?

N/A	0	10	20	30	40	50	60	70	80	90	100
□	□	□	□	□	□	□	□	□	□	□	□
	No soy capaz de hacerlo en absoluto				Soy capaz de hacerlo moderadamente				Estoy seguro de que soy capaz de hacerlo		

8- ¿Hasta qué punto cree que usted es capaz de controlar el pensar en qué vida tan buena tuvo antes de la enfermedad de su familiar y cuánto ha perdido debido a ello?

N/A	0	10	20	30	40	50	60	70	80	90	100
□	□	□	□	□	□	□	□	□	□	□	□
	No soy capaz de hacerlo en absoluto				Soy capaz de hacerlo moderadamente				Estoy seguro de que soy capaz de hacerlo		

9- ¿Hasta qué punto cree que usted es capaz de controlar el pensar sobre lo que se está perdiendo o a lo que está renunciando por cuidar de su familiar?

N/A	0	10	20	30	40	50	60	70	80	90	100
□	□	□	□	□	□	□	□	□	□	□	□
	No soy capaz de hacerlo en absoluto				Soy capaz de hacerlo moderadamente				Estoy seguro de que soy capaz de hacerlo		

10- ¿Hasta qué punto cree que usted es capaz de controlar el preocuparse sobre problemas futuros que pueden surgir debido al cuidado?

N/A	0	10	20	30	40	50	60	70	80	90	100
□	□	□	□	□	□	□	□	□	□	□	□

No soy capaz de hacerlo en absoluto	Soy capaz de hacerlo moderadamente	Estoy seguro de que soy capaz de hacerlo

Frecuencia de comportamientos problemáticos

Por favor indique si alguno de estos problemas le ha ocurrido durante la semana pasada a su familiar y cuánto le ha molestado, disgustado o estresado cuando han sucedido.

Frecuencia
0 = nunca ocurrió
1 = Ocurrió, pero no la semana pasada
2 = 1 ó 2 veces la semana pasada
3 = de 3 a 6 veces la semana pasada
4 = diariamente o más a menudo

Reacción
0 = no me estresó nada
1 = Me estresó un poco
2 = me estresó moderadamente
3 = me estresó mucho
4 = me estresó extremadamente

Conducta	**Frecuencia**	**Reacción**
1. Repite la misma pregunta una y otra vez.	0 1 2 3 4	0 1 2 3 4
2. Tiene dificultades para recordar acontecimientos recientes.	0 1 2 3 4	0 1 2 3 4
3. Tiene dificultades para recordar acontecimientos del pasado.	0 1 2 3 4	0 1 2 3 4
4. Pierde objetos o no recuerda donde los dejó	0 1 2 3 4	0 1 2 3 4
5. Olvida el día en el que vive.	0 1 2 3 4	0 1 2 3 4
6. No finaliza las cosas ni las actividades que comienza.	0 1 2 3 4	0 1 2 3 4
7. Tiene dificultades para concentrarse en una tarea.	0 1 2 3 4	0 1 2 3 4
8. Rompe y estropea objetos propios o ajenos.	0 1 2 3 4	0 1 2 3 4
9. Realiza acciones embarazosas para usted.	0 1 2 3 4	0 1 2 3 4
10. Se levanta durante la noche y despierta a otros.	0 1 2 3 4	0 1 2 3 4
11. Habla demasiado alto y deprisa.	0 1 2 3 4	0 1 2 3 4
12. Se muestra ansioso o preocupado.	0 1 2 3 4	0 1 2 3 4
13. Realiza actividades que resultan peligrosas para él mismo o para otras personas.	0 1 2 3 4	0 1 2 3 4
14. Amenaza con causarse daño a sí mismo.	0 1 2 3 4	0 1 2 3 4
15. Amenaza con causar daño a otras personas.	0 1 2 3 4	0 1 2 3 4
16. Se muestra verbalmente agresivo con otras personas.	0 1 2 3 4	0 1 2 3 4
17. Tiene aspecto triste o deprimido.	0 1 2 3 4	0 1 2 3 4
18. Expresa sentimientos de desesperación o tristeza acerca del futuro (Ej: “nada merece la pena”; “nunca me salen bien las cosas”).	0 1 2 3 4	0 1 2 3 4
19. Llora o se muestra lacrimoso.	0 1 2 3 4	0 1 2 3 4

Conducta	**Frecuencia**	**Reacción**
20. Realiza comentarios acerca de la muerte de él mismo o de los demás (Ej: "sería mejor que me muriera")	0 1 2 3 4	0 1 2 3 4
21. Expresa sentimientos de soledad.	0 1 2 3 4	0 1 2 3 4
22. Expresa sentimientos de inutilidad y se acusa de ser una carga para los demás.	0 1 2 3 4	0 1 2 3 4
23. Expresa sentimientos de fracaso y de no haber realizado nada valioso durante su vida.	0 1 2 3 4	0 1 2 3 4
24. Discute, protesta o se muestra irritable.	0 1 2 3 4	0 1 2 3 4

Nivel funcional

Hasta qué punto su familiar es capaz de realizar las siguientes actividades:

COMER:

(10) Independiente. Capaz de comer por sí solo y en un tiempo razonable. La comida puede ser cocinada y servida por otra persona.

(5) Necesita ayuda. Para cortar la carne o el pan, extender la mantequilla, etc., pero es capaz de comer solo.

(0) Dependiente. Necesita ser alimentado por otra persona.

LAVARSE (BAÑARSE):

(5) Independiente. Capaz de lavarse entero. Incluye entrar y salir del baño. Puede realizarlo todo sin estar una persona presente.

(0) Dependiente. Necesita alguna ayuda o supervisión.

VESTIRSE:

(10) Independiente. Capaz de ponerse y quitarse la ropa sin ayuda.

(5) Necesita ayuda. Realiza solo al menos la mitad de las tareas en un tiempo razonable.

(0) Dependiente.

ARREGLARSE:

(5) Independiente. Realiza todas las actividades personales sin ninguna ayuda. Los complementos necesarios pueden ser provistos por otra persona.

(0) Dependiente. Necesita alguna ayuda.

DEPOSICIÓN:

(10) Continente. Ningún episodio de incontinencia.

(5) Accidente ocasional. Menos de una vez por semana o necesita ayuda para enemas y supositorios.

(0) Incontinente.

MICCIÓN (Valorar la semana previa):

(10) Continente. Ningún episodio de incontinencia. Capaz de usar cualquier dispositivo por sí solo.

(5) Accidente ocasional. Máximo un episodio de incontinencia en 24 horas. Incluye necesitar ayuda en la manipulación de sondas y otros dispositivos.

(0) Incontinente..

USAR EL RETRETE:

(10) Independiente. Entra y sale solo y no necesita ningún tipo de ayuda por parte de otra persona.

(5) Necesita ayuda. Capaz de manejarse con pequeña ayuda: es capaz de usar el cuarto de baño. Puede limpiarse solo.

(0) Dependiente. Incapaz de manejarse sin ayuda mayor.

TRASLADO AL SILLON/CAMA:

(15) Independiente. No precisa ayuda.

(10) Minima ayuda. Incluye supervisión verbal o pequeña ayuda física.

(5) Gran ayuda. Precisa la ayuda de una persona fuerte o entrenada.

(0) Dependiente. Necesita grúa o alzamiento por dos personas. Incapaz de permanecer sentado.

DEAMBULACION:

(15) Independiente. Puede andar 50 m, o su equivalente en casa, sin ayuda o supervisión de otra persona. Puede usar ayudas instrumentales (bastón, muleta), excepto andador. Si utiliza prótesis, debe ser capaz de ponérsela y quitársela solo.

(10) Necesita ayuda. Necesita supervisión o una pequeña ayuda física por parte de otra persona. Precisa utilizar andador.

(5) Independiente. (En silla de ruedas) en 50 m. No requiere ayuda o supervisión.

(0) Dependiente.

SUBIR / BAJAR ESCALERAS:

(10) Independiente. Capaz de subir y bajar un piso sin la ayuda ni supervisión de otra persona.

(5) Necesita ayuda. Precisa ayuda o supervisión.

(0) Dependiente. Incapaz de salvar escalones

Carga

	Nunca	Rara vez	Algunas veces	Bastantes veces	Casi siempre
1. ¿Piensa que su familiar le pide más ayuda de la que realmente necesita?					
2. ¿Piensa que debido al tiempo que					

	Nunca	Rara vez	Algunas veces	Bastantes veces	Casi siempre
dedica a su familiar no tiene suficiente tiempo para Vd.?					
3. ¿Se siente agobiado por intentar compatibilizar el cuidado de su familiar con otras responsabilidades (trabajo, familia)?					
4. ¿Siente vergüenza por la conducta de su familiar?					
5. ¿Se siente enfadado cuando está cerca de su familiar?					
6. ¿Piensa que el cuidar de su familiar afecta negativamente la relación que usted tiene con otros miembros de su familia?					
7. ¿Tiene miedo por el futuro de su familiar?					
8. ¿Piensa que su familiar depende de Vd.?					
9. ¿Se siente tenso cuando está cerca de su familiar?					
10. ¿Piensa que su salud ha empeorado debido a tener que cuidar de su familiar?					
11. ¿Piensa que no tiene tanta intimidad como le gustaría debido a tener que cuidar de su familiar?					
12. ¿Piensa que su vida social se ha visto afectada negativamente por tener que cuidar a su familiar?					
13. ¿Se siente incómodo por distanciarse de sus amistades debido a tener que cuidar de su familiar?					
14. ¿Piensa que su familiar le considera a usted la única persona que le puede cuidar?					
15. ¿Piensa que no tiene suficientes ingresos económicos para los gastos de cuidar a su familiar, además de sus otros gastos?					
16. ¿Piensa que no será capaz de cuidar a su familiar por mucho más tiempo?					

	Nunca	Rara vez	Algunas veces	Bastantes veces	Casi siempre
17. ¿Siente que ha perdido el control de su vida desde que comenzó la enfermedad de su familiar?					
18. ¿Desearía poder dejar el cuidado de su familiar a otra persona?					
19. ¿Se siente indeciso sobre qué hacer con su familiar?					
20. ¿Piensa que debería hacer más por su familiar?					
21. ¿Piensa que podría cuidar mejor a su familiar?					
22. Globalmente, ¿qué grado de "carga" experimenta por el hecho de cuidar de su familiar?					

Depresión

A continuación se le presentan unas frases que describen cómo usted podría haberse sentido durante la semana pasada**.**

	Raramente o nunca (menos de 1 día)	**Alguna vez o pocas veces (1 o 2 días)**	**Ocasionalmente o varias veces (3 o 4 días)**	**Todo el tiempo (5-7 días)**
1- Me molestaron cosas que habitualmente no me molestan				
2- No tuve hambre; tenía poco apetito.				
3- Sentía que no podía librarme de la tristeza incluso con la ayuda de mi familia o amigos.				
4- Sentí que era, al menos, tan bueno como otras personas.				
5- Tuve problemas para concentrarme en lo que hacía.				
6- Me sentí deprimido.				
7- Sentí que todo lo que				

	Raramente o nunca (menos de 1 día)	**Alguna vez o pocas veces (1 o 2 días)**	**Ocasionalmente o varias veces (3 o 4 días)**	**Todo el tiempo (5-7 días)**
hacía era un esfuerzo.				
8- Me sentí optimista sobre el futuro.				
9- Pensé que mi vida había sido un fracaso.				
10- Me sentí temeroso.				
11- Mi sueño era inquieto, no descansaba.				
12- Estaba contento.				
13- Hablaba menos de lo habitual.				
14- Me sentí solo/a.				
15- La gente me resultaba antipática.				
16- Disfruté la vida.				
17- Lloré en ocasiones.				
18- Me sentí triste.				
19- Sentí que no le gustaba a la gente.				
20- No tenía ganas de nada.				

Ansiedad

A continuación le voy a leer una lista de palabras que describen cómo se pueden sentir las personas. Por favor, indique hasta qué punto se ha sentido usted así la durante la **semana pasada**:

	Nada	**Un poco**	**Moderadamente**	**Bastante**	**Muchísimo**
Tenso/a					
Agitado/a					
A punto de estallar					
Descontrolado/a					
Relajado/a					

Intranquilo/a					
Inquieto/a					
Nervioso/a					
Ansioso/a					

Motivos Culturales para el Cuidado

Cuido de mi familiar ...

	Totalmente en desacuerdo	Algo en desacuerdo	Algo de acuerdo	Totalmente de acuerdo
1) Porque es mi obligación cuidar a personas mayores de la familia dependientes				
2) Porque es importante dar ejemplo a los hijos de la familia				
3) Porque fui educado por mis padres para cuidar a las personas mayores de la familia con dependencia				
4) Debido a mis creencias religiosas y espirituales				
5) Porque cuidando a los familiares mayores dependientes devuelvo lo que se me ha dado a mí.				
6) Porque fortalece los lazos o vínculos entre ellos y yo.				
7) Porque fui criado para creer que el cuidado debe ser proporcionado en la familia				
8) Porque es lo que "mi gente" siempre ha hecho				
9) Porque siento que estoy siendo útil y realizando una contribución a la familia				
10) Porque mi familia espera de mí que cuide				
11) Porque no me queda otra opción				

Rumiación

Las personas nos diferenciamos, entre otras cosas, en lo que pensamos y hacemos cuando estamos tristes, abatidas o melancólicas. Por favor, escuche atentamente cada una de las afirmaciones que aparecen a continuación y, tras cada una de ellas, indique la frecuencia con la que usted piensa o actúa de esa manera, indicando si no lo hace nunca, si lo hace algunas veces, con frecuencia o siempre que se encuentra triste, abatido/a o melancólico/a. Por favor, **piense en cómo se comporta usted, no en cómo cree que debería comportarse**

	Nunca	**A veces**	**Frecuentemente**	**Siempre**
1.Piensa en lo solo/a que se siente				
2.Piensa en sus sentimientos de cansancio y dolor				
3.Piensa en lo difícil que le resulta concentrarse				
4.Piensa en lo apático/a y desganado/a que se siente				
5. Piensa: "¿Por qué no puedo seguir adelante?"				
6. Piensa en una situación negativa reciente, deseando que las cosas hubieran ido mejor				
7. Piensa en lo triste que se siente				
8. Piensa en todos sus fracasos, sus fallos, sus errores y defectos				
9. Piensa en lo poco que le apetece hacer nada				
10. Piensa: "Pero, ¿por qué no puedo manejar mejor las situaciones?"				

Reevaluación cognitiva

	Nunca	**A veces**	**Frecuentemente**	**Siempre**
1. Aunque a veces me siento triste, suelo tener una visión optimista				
2. Aunque me sienta mal, procuro pensar en cosas agradables				
3. Cuando estoy triste, pienso en todos los placeres de la vida				
4. Intento tener pensamientos positivos aunque me sienta mal				

Ira

	No, en absoluto	**Algo**	**Moderadamente**	**Mucho**
Tengo un carácter irritable				
Soy una persona exaltada				
Me molesta cuando hago algo bien y no me lo reconocen				
Tiendo a perder los estribos				
Me pone furioso que me critiquen delante de los demás				
Me caliento rápidamente				
Me siento furioso cuando hago un buen trabajo y se me valora poco				
Me cabreo con facilidad				
Me enfado si no me salen las cosas como tenía previsto				
Me enfado cuando se me trata injustamente				

Activación Conductual

Durante el **mes pasado**, hasta qué punto ha realizado alguna de las siguientes actividades:

	Nada	**Un poco**	**Termino medio**	**Bastante**	**Mucho**
Estar tranquilo					
Ir a la iglesia u otras reuniones de grupos u organizaciones					
Aficiones u otros intereses					
Ir a comer o cenar fuera o a otras actividades sociales					
Pasar buenos ratos con otras personas					
Visitar a la familia y/o amigos					

Satisfacción Conductual

Durante el **mes pasado**, hasta qué punto ha estado satisfecho con la cantidad de tiempo que ha sido capaz de dedicar a:

	Nada satisfecho	**Un poco satisfecho**	**Muy satisfecho**
Estar tranquilo			
Ir a la iglesia u otras reuniones de grupos u organizaciones			
Aficiones u otros intereses			
Ir a comer o cenar fuera o a otras actividades sociales			
Pasar buenos ratos con otras personas			
Visitar a la familia y/o amigos			

Salud física percibida

En la actualidad, ¿cómo considera usted su salud?

Muy mala **Mala** **Normal** **Buena** **Muy buena**

Riesgo de institucionalización del familiar

Durante esta última semana, ¿ha pensado en la posibilidad de ingresar a su familiar en una residencia?

0	10	20	30	40	50	60	70	80	90	100
No lo he pensado en absoluto					Un día sí, otro no					Lo he pensado todos los días